HEALTH CARE CONSUMPTION: A COMPARISON OF TRADITIONAL AND ALTERNATIVE CANCER TREATMENT CENTERS

A Dissertation

by

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ABSTRACT

In recent years, there has been a shift toward utilization of alternative medicine in the U.S. In the context of our changing health care system, it is important to understand whether distrust or lack of progress in traditional medicine is pushing people away, or whether rapid progress in alternative medicine is pulling people toward it. This study uses a content analysis of alternative and traditional cancer treatment center websites, along with interviews of alternative and traditional physicians to illuminate the way websites appeal to potential health care consumers. These methods reflect consumer demand as well as the ways that alternative and traditional practitioners see the movement toward alternative medicine.

Content analysis showed that traditional and alternative cancer treatment websites use a combination of demonstrating competence and compassion to engender the trust of patients. These websites promote the things seen as their strengths and also the things they are perceived as lacking in order to appeal to clients; however, in this effort to appeal to a wider audience, they actually lose their unique identity and more closely resemble one another. The images and text of the websites imply that all aspects of treatment and, ultimately, success are the responsibility of the patient, regardless of access to resources.

Interviews revealed opposing viewpoints from each branch of medicine regarding practices of the opposite branch of medicine, particularly with respect to personalized care and the use of evidence based medicine. Other themes that emerged

were differential physician roles in patient care, different perspectives on trust, mixed feelings regarding the impact of available health information on the internet on doctor-patient relationships, the idea that insurance constrains the ability to provide care and, the idea that although physicians all believe that patients should have control of their care, they do not believe patients can be trusted to make those decisions.

The dynamic of all of these factors places the doctor-patient relationship in tenuous territory as there is a struggle over which type of medicine is best, whether the doctor or the patient knows best, and getting insurance companies to cover treatment that is necessary for the patients to survive.

DEDICATION

In memory of my father, who, with my mother, taught me that integrity and perseverance were the keys to any sort of success in life. Thank you both for teaching me to be strong and brave in the face of adversity, to stand on my own two feet, and to believe that anything is possible, no matter how many curve balls life throws at you. Because of you I am here; because of you, I endeavor to make a difference in the world—no matter how great or small—and because of you, I stand with my toes on the edge of an unknown precipice "with grace in my heart and flowers in my hair."

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CHAPTER I

INTRODUCTION

When Americans seek out health care, they face a myriad of choices regarding both the providers and the types of medicine. There has been an increasing availability of medicine that is presented as an alternative to the traditional medicine. "Approximately half of U.S. adults use alternative and complementary healing practices and therapies (CAM), either alone or combined with allopathic approaches." (Braun et al 2000: 177) In the early 1990s, Americans spent an estimated $27billion on alternative medical treatments. However, most of those expenditures were paid out of pocket rather than by health insurers (Tillman 2002). Why have complementary healing practices and therapies become so prominent? In particular, in the American context, why would people seek alternative sources of health information and practice? Is distrust or lack of progress in more traditional medicine pushing people away; is rapid progress in CAM pulling people toward the newer alternatives? The answers to these questions can help us understand how people make decisions of life and death matters and how practitioners evaluate and work with these decisions.

Health care, both traditional and CAM, is a large field and addresses a span of health concerns from birth and midwifery (Mitchell and McClean 2014) to palliative care and death (Schutze et al 2016). To narrow the scope of investigation, I focus on a particular group of illnesses that receive a great deal of attention and in which there is a rapid development in research and new therapies: cancer.

Cancer is usually viewed as a heinous disease that requires patients to engage in a lengthy battle using chemotherapy or radiation if one expects any chance of survival. Chemotherapy and radiation, themselves, are very taxing on patients and have side effects that vary in intensity, and are at times, debilitating. As a result, some patients have utilized CAM. However, traditional medicine has recently had advances to treatment such as Immunotherapy. Rather than attack cancer directly, as chemotherapy does, immunotherapy rallies the immune system to fight the disease. Simultaneously, as alternative medicine has shifted to being not only about eastern medicine, but also about alternative solutions to the same traditional medicine problems, CAM has also made immunotherapy part of its focus. While some alternative practitioners have received FDA approval for Immunotherapy drugs, the drugs are still expensive and not easily accessible to patients without insurance. (Chustecka 2015). Traditional treatment has used clinical trials as a means of making their immunotherapy drugs, called checkpoint inhibitors, more accessible to patient and has often used them in conjunction with chemotherapy and radiation with mixed success (Garner 2016). These shifts in cancer treatment and the overlap of such therapies make the decision about which treatment to use and the defining traits of each branch of medicine even more complex than even 5 years ago.

In this study, I compare traditional or medically associated cancer centers to "nontraditional' cancer centers that are not associated with medical facilities. In particular, I will examine common themes that emerge both in face-to-face interviews with traditional and CAM practitioners and in the manner in traditional and CAM

facilities represent (or advertise) their services. I examine how internet depictions of the different types of facilities portray their strengths and through either explicit or implicit comparison, portray the weakness of other approaches. In this manner, I illustrate what practitioners of both traditional and CAM organizations view as the most important aspects of their work with their clients. The analysis demonstrates that while both types of organizations recognize the other, and while practitioners may, at times, express nuanced understandings of each other, their representations of both themselves and the other are, for the most part, stereotypical. These representations have varying concepts, but they center on the issue of trust.

Most studies of CAM have been done outside of the US, including: the United Kingdom (Cincotta et al 2006, Broom and Tovey 2007, Broom and Tovey 2008, Smithson et al 2012, Tovey and Broom 2007), Canada (Keller and Wellman 1997, Balneaves et al 2007, Sirois and Gick 1982), Sweden (Hok et al 2007), Netherlands (van Kleffens et al 2004) and Australia (Cincotta et al 2006, Broom 2009, McGregor and Peay 1996) where individuals must pay for CAM out of pocket since they have universal health care(Kelner and Wellman 1997). Not only is a current study in the US adding to a lacking body of literature, but it is also important at this time, as we transition from the old system to The Patient Protection and Affordable Care Act.

Additionally, most research--especially in relation to cancer--has tended to describe patterns of usage rather than explore beliefs and understandings underlying motivation for use of CAM. (Broom and Tovey 2007) In fact, Broom (2009) argues for a more critical approach to the sociology of CAM, firmly grounded in experience,

particularly in the context of cancer. This research will not look at usage per se but rather at the experience of practitioners and the materials that are seen by clients. The inclusion of the physician/practitioner perspective will also add to the existing body of literature as most studies have been one-sided and/or little to no information was provided on the extent to which conventional providers either recommended or provided access to complementary and alternative therapies (Kessler et al 2001)

CHAPTER II

LITERATURE REVIEW

To compare traditional or medically associated cancer centers to "nontraditional' cancer centers that are not associated with medical facilities, along with the issues that are pertinent among professionals at these facilities, it is important to first consider the literature related to cancer treatment in these two branches of medicine. The following chapter discusses the existing literature on cancer, beginning with diagnosis and following through the treatment process, and the role of alternative and traditional medicine in that process, along with existing gaps in the literature.

Stressors and their impact on individual health

A stressor an environmental condition or event that elicits stress. Stressors can include monetary, work or marital problems or things like personal or family health or treatment for an illness (Antonovsky 1988) and have a physiological impact on our bodies. Included in those physiological reactions is the release of hormones (adrenaline, endorphins, etc.), which circulate and prepare the body for flight or fight response. This hormone increase leads to an increase in blood pressure and a release of energy from fats and simple carbohydrates (sugars). Additionally, the immune system depresses to allow the body to tolerate possible invasions like wounds (Seyle 1950) and McIntosh (1994) found that stressors increased lymphocyte and platelet counts in the elderly.

However, not everyone responds to stressors the same way. These differences can be found both in the physiological reactions individuals have to stressors and the way they manage the stressor (coping). Physiological differences include differences in

hormonal response and may be due to genetic differences among people, in general. Others argue that men and women react differently because of their biological differences (Lazarus 1984, 1993). Still others argue that early experiences may affect physiological reactions throughout life (as in the example of the memory of a frightening or traumatic event).

Individuals may also differ in their non-physiological reactions to stressors. According to Lazarus (1984, 1993), how we interpret a stressor affects how we react to it. So, based on the way we conceive of a particular stressor, we may respond in different ways—anger, fear, denial, action, in-action, etc. than others who are exposed to the same stressor. Antonovsky (1988) takes this idea that our perceptions of the stimuli rather than the stimuli itself are what triggers our response a bit farther. He postulates that stimuli from our environment are structured, predictable, and explicable. The resources are available for one to meet the demands posed by these stimuli and these demands are challenges worthy of investment and employment. People who have a high sense of coherence about this are healthier. However, culture and position in social structure may impact one's sense of coherence. The major critique of this approach is that it minimizes the very real physical nature of negative stimuli from the environment as well as the mental and physical health problems that can result from it.

Cancer diagnosis as stressor

While diagnosis has not become a distinctive area of research within the social sciences, we do have a basic idea of what that exchange entails. (Shaepe 2011) "The idealized clinical encounter is a cooperative interaction which brings patient and doctor

together in a kind of hand- shake agreement about what ails the former and what the latter can do in response. But it is not always so simple." (Jutel 2009: 294) This is particularly true when the interaction between doctor and patient involves the delivery of the news that the patient has cancer. According to Shaepe (2011: 912), "each year an estimated 1.4 million new cancer cases are diagnosed in the United States, and although the 5-year survival rate for many forms of the disease has improved, cancer remains one of the most feared diagnoses." Cancer and other such life threatening diseases challenge the taken for granted nature of time-orientation in the life of a patient and their loved ones, thereby challenging their sense of control. (Olson 2011) Hubbard et al's 2010 exploration of the experiences of people within the first year of their diagnosis with colorectal cancer utilizes the concept of biographical disruption—a descriptor of people's experiences of chronic illness and an explanatory device to comprehend how people respond and adapt to chronic illness—in order to understand cancer because it is a critical experience which upends people's taken for granted assumptions about their bodies, selves and the social world in which they reside. However, the effect of such a disruption of the life course timeline is highly contextual. (Hubbard et al 2010, McFarland et al 2013) People who have suffered loss or tragic events throughout their lives may anticipate these types of disruptions and experience their impact differently from those who have not. (Hubbard et al 2010) Age at diagnosis, as McFarland et al (2013) pointed out, may cause differential effects with younger adults having fewer safety nets than the elderly (who receive Medicare), more demands on their time and resources (children and families and work because they are in an earlier stage of their

life and not retired), and raise more existential questions for those who have not thought about their own mortality as much. The way that the news is delivered, the length of time the person has been experiencing symptoms without a diagnosis being made, and interaction with medical personnel all have an impact on the experience of cancer diagnosis.

Shaepe's 2011 analysis of patients' accounts of the day they learned their cancer diagnosis found that those accounts were "storied" and had a beginning, middle, and end, with a prefacing background to set it up either by: describing first symptoms, normal life just before diagnosis or episodes of a smooth or delayed diagnosis. All accounts were composed of 2 inter-related subtopics: patients multiple encounters with the medical system prior to diagnosis and the moment the patient or caregiver realized the news. Throughout these accounts, participants devoted more attention to the encounters with the medical system than to the diagnosis, itself, and these encounters played a very important part in the way the diagnosis was internalized. Beach et al (2005) analyzed video excerpts from encounters between patients and oncology doctors which revealed unease and anxiety in patients when being impacted by a potential brush with cancer—even when the news they received was good—particularly if physicians demonstrated what appeared to be uncertainty about answers to medical questions. While patients made it clear that they were experiencing emotional turmoil, doctors acknowledged the patients, yet exhibited minimal receptiveness to them. This sense of uncertainty coupled with a lack of verbal or physical reassurance appeared to impact patients by leaving them with an appearance of trepidation. (Beach et al 2005) Likewise, Olson (2011)

interviewed caregivers of spouses who had cancer about their experience of the cancer diagnosis and found that the delivery of the diagnosis and other conversations with doctors and nurses were important in shaping their outlook. "Hearing the diagnosis was said to be very visceral and memorable, thus it was an opportune time for medical professionals, knowingly or otherwise, to frame and guide patient (and carers') temporal orientations and subsequent emotions. (908) According to Shaepe (2011), trust is critical in these situations of diagnosis, and "is something sociologists understand to be actively negotiated between doctor and patient and reproduced through routine organizational practices. This study reveals that the medical encounters early in the diagnostic process served as a defining trust building or distrust building experience," (918) with the initial diagnosis having a long lasting effect on the doctor/patient relationship. Presence or absence of support from members of the medical system prior to diagnosis mattered a great deal. Support was described as the consistency of communication across settings, variability or consistency in clinician competence and whether or not the doctor was knowledgeable about their specific medical case. These initial impressions about the level of support, in turn, influenced patients and caregivers' trust in the doctors recommendations for treatment and affected patients sense of positivity or negativity about the future.

In light of the critical nature of diagnosis and even the interactions leading up to that diagnosis, physician guidelines on this patient-doctor interaction of delivering bad news advise doctors to take care in their selection of where they disclose the news, respond with empathy, and the need to deliver bad news in increments, hinting at what's

to come, a process referred to as "forecasting." (Maynard 1996, Shaepe 2011) Through verbal and nonverbal behavior physicians try to lessen the shock of the diagnosis, easing the recipient into realization (Maynard 1996, 2003) In Olson's study (2011), diagnosis was cast by medical professionals as ranging from certainly bleak (a very bad outlook that shamed patients into action because they had ignored their symptoms), probably survival(a positive prognosis which kept patients focusing on good things or accepting circumstances) and gradual (often a great deal of information was given at once, then gradually less information was given at less frequent intervals, as the prognosis was not so good) The gradual diagnosis placed patients in a state of what was described as "long temporal anomie," where everything was uncertain and they weren't sure how to proceed or make meaning of things. This particular method of disseminating the diagnosis made patients trust physicians less due to the fact that they were withholding information.

In traditional medical settings, while routines of who delivers what news when and to whom as part of the organization of making an official diagnosis are a means to accomplish difficult professional tasks, they are also part of the process of making a sound diagnosis. The process generally involves more than one clinician in different clinic settings dispersing bits of the news at a time, as they are available and verified, leading up to the final diagnosis once all tests are complete and results are definitive. (Shaepe 2011) As evidenced by Gross' 2009 study of the process and delivery of brain cancer diagnosis, information changes hands among many professionals including technicians, staff and specialists as it is examined and conclusions are drawn. Radiology

first sees the mass or tumor, then histopathology does the biopsy and, in the process of removing it, removes the tissue from the actual person and accomplishes social distancing. Meanwhile, a clinical exam achieves the physical exam and gathers history and information from the patient and a neuropsychologist does diagnostics for patients who seem to suffer cognitive or emotional deficiencies related to the organic effects of the tumor (and later, the treatment provided for it). As evidenced here, diagnosis is generally a lengthy process that sometimes takes awhile to be translated to patients and, when it finally is, it can be confusing and alienating.

A gap exists between what physicians think they convey and what patients understand from the diagnosis. (Shaepe 2011: 913) For this reason, Bylund et al (2010) argue for the importance of concordance—the shared understanding between physician and patient. Concordance can be viewed as a two way cooperative communication process where shared meaning is negotiated between the two actors, who are experts in their own domain (the patient in their own symptoms and body, the physician in various treatment options and medicine). Concordance is seen as having potential to improve doctor/patient communication and relationships, but it is still a goal to strive for as evidenced in the research.

When comparing patient related concerns of AYA (Adolescent and Young Adult) oncology patients to oncology professionals perceptions of them, Thompson et al (2013) found that healthcare professionals were not in sync with what AYA patients were focused on. While physicians were focused on information about survival and care delivery as primary concerns to patients, patients were primarily concerned about

whether or not they would be able to go to college or how illness would effect employment. Blaxter (2009), in her examination of the effects of technology on the process of diagnosis for individuals with lung cancer, found that the image that allows detection of cancer can actually obscure the person who is suffering from the illness. "The patient is not seen as a coproducer of the diagnosis, or owner of the evidence and is not thought to have any special knowledge to contribute to its interpretation." (774) While patients may influence the actual process of diagnosis, they are "denied the status of expertise: the expert is the reader of the body and the deciphering agent of the narrative." (Gross 2009: 1822) In Blaxter's (2009) case, few of the clinicians encountered seemed to ignore the patient's integrity as an individual. It is not a question of miscommunication or brushing aside the patient's view, but rather the sanctity of the evidence in a realm where the measurement and the image (as opposed to doctor and patient), "is increasingly becoming the vehicle of decisions. Thus, the patient is less likely to be offered any real choice--except the ultimate choice of refusing treatment altogether." (774)

In spite of the potential for feelings of alienation, whenever the diagnosis is given, it can sometimes be a relief at the end of a long process of being ill, but not knowing what, exactly, was wrong. Patients can gain a sense of validation for seeking medical help and the confirmation that something was wrong with them, as they had suspected, along with the recognition of their ailment as a legitimate medical condition. (Willig 2011, Van Schalkwyk et al 2008, Forsyth et al 2011) Receiving a diagnosis entitles patients to take up Parson's sick role, which can also lead to a reduction in stress

for the patient as it relieves them from certain duties (work, etc.) that may have been difficult to perform with their illness. The diagnosis, especially one as powerful as that of cancer, can lead individuals to enhance personal relationships, have a greater appreciation of life, increase a sense of personal strength, enhance their spirituality and change their priorities in life. Thus, diagnosis need not be all limiting and constraining as it does have the potential to facilitate relief and positive changes. (Willig 2011)

However, the fact remains that diagnosis also has an impact on patients' psychological well-being and can impact their levels of perceived control. Ranchor et al (2010) examined patients' perceptions of control before and after their cancer diagnosis and found that perceived control (as measured by the Mastery Scale) decreased sharply after diagnosis and even after a year, though there were improvements in their perceptions of control, they did not return to their original levels. One way of conceptualizing a cancer diagnosis is as a chronic stressor, which arises as a discrete life event, but continues to create stress long after the event has passed (consequences of diagnosis, fear of recurrence, loss of functioning). "Although not all individuals view their diagnosis as traumatic, a cancer diagnosis has the potential to radically alter an individual's self-concept (Curbow et al 1990, Hubbard et al 2010, McFarland et al 2013), threaten an individual's sense of independence (Hubbard et al 2010) and shatter the notion that individuals are able to understand the causes of their experience." (McFarland et al 2013) A cancer diagnosis can evoke fear of suffering, disfigurement, debilitating treatment, and loss of functioning (Heidrich et al., 1994) and many individuals with cancer feel powerless and express uncertainty about their path toward

improvement (Kaiser, 2008). Spouse caretakers of cancer patients reported a lack of control and loss of direction as a consequence of cancer diagnosis. In fact, the hindered ability to plan left caretakers feeling confused and guilty, in a temporal position of stasis that Olson (2011) calls "temporal anomie": a challenged orientation towards time based on Durkheim's use of the word to describe the sense of normlessness and lost direction that people experience after major events. (907)

In order to move forward, patients (and caretakers) have to figure out how to function within the context of cancer discourse. According to Willig (2011), cancer takes the form of a trajectory that involves a series of moments, of which diagnosis is but one. As patients move along in their journey, each moment or stop involves a shift in stance toward cancer and their needs change as their understanding of cancer changes. Diagnosis, as one of the first stops on the journey, tends to give rise to the desire for information. It is a time when patients have to construct the entirely new identity for themselves of cancer patient. As told by caretakers of those diagnosed with cancer, absorbing the diagnosis was described as a 2-fold process: intellectual understanding came shortly after hearing the news, but deeper emotional realization came separately and sometimes even after treatment had commenced. (Shaepe 2011)

Willig (2009) self-describes her experiences of attempting to construct and make sense of a narrative that made sense of what was happening in the midst of emotional turmoil and uncertainty in her diagnosis with cancer. After diagnosis, she realized that not all available ways of making sense of her experience were helpful to her. In her follow study in 2011, she focuses on how a medical diagnosis positions the patient in

relation to healthy others in society rather than in relation to medical professionals, which is the more common focus in this area (Blaxter 2009), and examines the repercussions of such positions for those who find themselves in them. She is also concerned with the narrative struggle (what constitutes a legitimate narrative), which takes place once a person has been thrown into the discursive space available to those diagnosed with cancer within a particular socio-cultural context. This context includes increasingly frequent media coverage of cancer survivor stories of celebrities and ordinary people; the North American cultural imperative to 'think positively,' which includes the idea that death as a possible outcome is not to be acknowledged or talked about; and an environment in which positivity seems to be mandatory to the point where unhappiness requires some sort of apology. This discourse manifests itself in a war analogy and use of military metaphors--patients should fight a war against cancer and cancer should not just be accepted-it must be fought. (Willig 2011, Baszager 2012, Radley and Payne 2009) Likewise, the "imperative to think positively also privileges a restitution narrative which constructs illness as an interruption to the normal state of being, which is health." To accept illness/cancer is not socially acceptable. (Willig 2011) This creates a struggle for meaning after cancer diagnosis, both internally (what does it mean to the individual that they have been diagnosed with cancer?) and externally (how do others see the person now that they are a cancer patient?). This illustrates that the loss of meaning is so pervasive that there is even a sense of loss of control of the narrative, which will, eventually, make sense of the patients' experience of being diagnosed with cancer.

Being diagnosed with cancer is, indeed, a very complex and stressful interaction. "It is not just the burden of undergoing the treatment options—patients reveal that it is difficult to face an uncertain and potentially dreaded future with seemingly little control." (Beach et al 2005:905) The introduction of this stressor and the very nature of its introduction can have profound effects on the patient's sense of control and the course of action they choose to take in response, not only as they internalize the news and reconfigure their identities, but as they choose their method of coping with or treating the disease.

Coping and coping mechanisms

Part of responding to stressors lies in the management of them. This management of stressors or the more generalized way that people deal with problems in their everyday lives is referred to as coping. Coping is the means by which people cope with the tension produced by stressors and can be done in a variety of ways.

Lazarus (1993 & 1984) asserts that there are two functions of coping: problem-focused and emotion-focused. (Ferrari et. al. 2003, Olson 2011, Vitalliano et. al. 1993) Emotion-focused coping is done to either change the way the stressor is attended to or to reappraise the relational meaning of what is happening. Put differently, this type of coping makes the stressor less threatening without actually changing the stressor in any way. In essence, individuals are reinterpreting their stressors or situations in a way that is more appealing to them. (Mount 1993) Anorexics may reinterpret their disease as a means of controlling their weight or a way to gain things they are lacking (Epeset et. al.

2006) or parents may reinterpret symptoms of their child's autism as creativity. (Brock and Sader 2008)

In a study of patient perceptions of chemotherapy over 8 months in a cancer support group in western Canada, Bell (2009) found that patients had reconfigured the experience of suffering and pain in chemotherapy as a sign of how well it was working, in spite of being advised to the contrary by medical professionals. This construction was seen as occurring because of a need for suffering to take meaning and purpose. Among caregivers of cancer patients, Olson (2011) found that carers used a range of coping strategies including distraction-to push their mind away from fears and negative thoughts and toward other things--or focused on the present or future and reinterpreting their perception of the cancer diagnosis in order to cope with their sense of interruption and purposelessness toward time. On the other side of the spectrum, a broader example of emotion-focused coping is coping with humor.

Humor is one commonly cited means of dealing with stressors. Taking a humorous outlook on life is thought to lessen anxiety and depression and increase self-esteem. Marziali et al. (2008) found that the more elderly made positive use of humor, the fewer depression and anxiety symptoms they had. Research shows that patients cope with illness better if they make positive use of humor. Positive use of humor is more about reinterpreting the situation to one that is less threatening to the individual. In contrast, detrimental humor-enhancing one's self at the expense of others or the use of humor in an excessively self disparaging way is not linked to enhanced coping abilities. Such coping strategies are not limited to use by patients. Those in medical professions

also use humor to deal with the stressors related to working with sick and dying patients (Wear 2006). Marziali et.al. (2008) speculate that perhaps those who feel they have greater control over their lives (be it physician or patient) tend to make use of humor to help them deal with health issues by joking about negative side effects or outcomes of treatments and procedures and making light of an otherwise serious or unpleasant situation.

The other function of coping is fulfilled by problem focused coping, that is, taking action against problems rather than reappraising their meaning. In Western culture, this function of coping seems to be more highly valued than emotion-focused coping. (Lazarus 1993) This action-based coping takes many forms including seeking treatment or medical care (Aschan and Punamaki 1994, Azarow et. al. 2005, Jonnson et.al. 2008, Karp 1992), information seeking(Azarow et. al. 2005, Chou and Wister 2005, Forkner-Dunn 2003, Gerber and Eiser 2001, Jonnson et.al. 2008), self care(Aschan and Punamaki 1994, Cartwright and Torr 2005, Chou and Wister 2005, Jonnson et.al. 2008, Karp 1992) and social support(Azarow et. al. 2005, Boehmer et. al. 2007, Brondolo et. al. 2009, Karp 1992, Lincoln 2007,McFarland et al 2013, Mount 1993). Cancer, with its often painful therapies and uncertain outcomes, causes a great deal of emotional distress. In order to control the emotional distress associated with a cancer diagnosis, patients may turn to prayer or connecting with family and friends (DiIoro 2011, McFarland et al 2013)

The internet is another resource individuals tend to tap into for all types of problem focused coping strategies, particularly information seeking. (Stadler and

Bromme 2007, Gould et. al. 2002, Walshe 2003) Information gathering becomes a strategy to reduce feelings of uncertainty and produce feelings of control and hope, particularly in groups where patients pool knowledge online in a virtual environment. (Radin 2006) Though the internet and direct access to medical and health related information has the power to enlighten individuals, it also has the potential to complicate doctor patient interactions (Gage and Panagakis 2012) because the internet offers different sources of knowledge than just their physician. (Gage and Panagakis 2012, Walshe 2003) However, many consumers of internet information do utilize this coping mechanism in conjunction with others such as medical care and social support. (Gould et. al. 2002)

The increase of such coping styles emphasizing individual initiative in dealing with health related and medical stressors has led to a shift away from a view of patients as passive recipients of care and services and toward a more active and critical consumer of health care and information (Aschan and Punamaki 1994, Azarow et. al. 2005, Gage and Panagakis 2012, Montague 2010, Lupton 1997, Sinding et al 2010, Radley and Payne 2009) With this shift has also come a decline in trust in physicians and, as such, patients are encouraged to be self-advocates and participate as equals in medical decision making, challenging the expert knowledge of their physicians and enhancing their sense of empowerment. (Gage and Panagakis 2012) These ideas of personal responsibility and control lead to an emphasis on self efficacy.

Self efficacy/mastery

Self efficacy reflects the perception of having control over one's environment. Those with lower self efficacy often believe in fate or the control of powerful others, thus believing that they cannot alter their circumstances. Those with high self efficacy believe they can alter contexts. The degree to which one has self efficacy is thought to influence the amount of effort invested in and the level of perseverance in overcoming challenging situations. (Azarow et.al. 2005, Bandura 1982)

Mastery (Majer et.al. 2003), is a term often used interchangeably with self-efficacy. Mastery has been found to be a key element in preventing and recovering from illness as it is associated with daily self-care practices and an overall healthier lifestyle. (Aschan and Punamaki 1994, Antonovsky 1988, Abrahamson 1978) There is a tendency in the literature to refer to mastery in a more broad, all-encompassing sense and to distinguish specific types of self efficacy such as abstinence self efficacy, emotional self efficacy, etc. (Azarow et.al. 2004, Majer et.al. 2007) For the purposes of this discussion, I will use self-efficacy and mastery interchangeably (as they have been cited in the research utilized) unless the research dictates a distinction between the types of self-efficacy.

Self efficacy/mastery has been found to be associated with better health (Marziali et al. 2008). People with high levels of mastery deal with stress more effectively than people with low levels. Thus, mastery is said to mediate the effect of stress on health outcomes. For instance, when a patient undergoes surgery, they have to cope with not only surgery, but also the treatment in the aftermath of surgery. Depending on the type

of surgery and treatment, this may continue for quite some time. Boehmer et.al. (2007) believe that mastery or perceived self-efficacy is the key for dealing with such adaptations and that it is the perception of being in control that is important. Those who have a high sense of mastery or self efficacy are more likely to make useful responses to their situation by adjusting to their physical situation (problem-focused coping) or attempting to utilize emotion-focused coping (positive reinterpretation or acceptance) Boehmer et.al. (2007) found that the stronger patients believed in their ability to cope with the difficult demands in life, the more they engaged in both problem and emotion-focused coping. The general findings of this study-that a greater sense of self efficacy or mastery have a positive impact on health and coping with health related problems-have been replicated in many similar studies. (Seeman and Seeman 1983, Revenson and Schiafmo 1992, Fu et.al. 2006, Jonnson et.al. 2008, Ranchor et al 2010)

Other studies have found that self efficacy can also have an impact on the quality of patient interaction with physicians (Han et.al. 2005, Zacharie et.al. 2003), with individuals with greater emotional self efficacy experiencing fewer problems with their interactions and feeling more satisfied with their physicians. (Han et.al. 2005) Simultaneously, lower levels of self-efficacy can have a negative impact on patient-physician interaction.(Han et.al. 2005)

Problematic levels of mastery/self efficacy

It is well established that higher levels of self-efficacy can have positive effects on coping and the converse, that lower levels of self-efficacy can have negative effects

on health. (Bahro et.al. 1995) So how do we strike a balance between too little and too much and is there such a thing as too much?

Even when utilizing the coping strategy of help-seeking, there are threats to individual self-efficacy. Difficulties communicating with physicians and nurses can decrease the sense of a patient's self efficacy. (Angermeyer et.al. 1999, Zachariae et.al. 2003) In fact, one of the primary reasons for the development of self-care groups has been the failure of the health care system to give patients give control over their own treatment. Thus, self-care provides the opportunity to not only regain control, but to regain some semblance of personal mastery/self efficacy within a system and at a time that they may feel helpless. (Aschan and Punamaki 1994) As this has become more wide-spread, so, too, has the lay knowledge regarding illnesses and their treatment. (Aschan and Punamaki 1994) With the growth of this knowledge and its dissemination come new challenges, particularly the possibility for misinformation, misinterpretation, incorrect self-diagnoses and consumer exploitation. (Walshe 2003) Thus, in the struggle to regain mastery/self-efficacy, there are risks.

If an individual had a heightened sense of mastery or self-efficacy, I would argue that it is possible that they would seek to solve their problems on their own and see utilizing the care of a physician as unnecessary. As previously mentioned, this could lead to a problematic or incorrect self diagnosis or a lack of care entirely.

Some illnesses, if treatment is put off, can end up being far more serious than would've been necessary if treatment had been sought more promptly. (Clark 2001) In some cases, the illness itself is a means of gaining control. In the case of Anorexia

Nervosa, patients gain a sense of mastery from their dieting and exercising behavior, which is a self directed course of action intended to cope with the perception of weight gain. (Epeset et.al. 2006) Thus, their sense of mastery is strong enough to direct them to this particular course of action and is then strengthened by their course of action. This enhances the seriousness of the situation by adding to their positive perception of this course of action and leads us to wonder if there can be such a thing as too much of a sense of mastery.

Treatment options

While people will certainly be predisposed to choose certain types of treatments, before a decision can be made as to which treatment route to take, patients must be aware of the variety of options that exist.

What is biomedical/traditional treatment?

Once an individual has gone through the process of assessing symptoms, seeing a general practitioner, getting referred to a specialist and diagnosed with cancer, the treatment that is commonly recommended by these physicians is what is referred to as traditional or biomedical treatment. Traditional treatment includes radiation, chemotherapy, hormone treatment and other targeted cancer therapies (drugs that block the growth and spread of cancer by interfering with specific molecules involved in the process by which normal cells are transformed into cancer cells and tumor growth), cell and bone marrow transplantation, and surgeries to remove tumors or prevent the spread of cancerous tissue (Pinedo 1997, National Cancer Institute: 2014). Treatment typically continues until the patient reaches a state of remission and the cancer is eliminated, or

physicians determine that no amount of treatment will stop the spread of the cancer. At this point, decisions must be made as to whether or not to continue treatment to prolong life, reduce tumor size or alleviate symptoms. (Angiola and Bowen 2013)

Whether to stop or pursue treatment in the face of certain death has been a central issue in medical oncology since the early 1950's. Baszager (2012) traces how these issues regarding the limits of treatment at the end of life were defined and the ways the dilemma was transformed through 3 different moments in the links between chemotherapy and palliation through evolving clinical research and innovative therapies. Palliation, or palliative care, in the context of cancer is to alleviate suffering. In the 50's, all treatment for cancer was palliative and the question was whether chemotherapy prolonged life or prolonged suffering. Clinical research saw the possibility of a cure on the horizon and palliation (as it is defined here) was second to the possible benefits of chemotherapy. Once the shift to a cure became the goal of chemotherapy, palliation became associated with the hospice movement and end of live comfort. Finally, in the 1980's, a debate arose within research about whether or not attention should be directed toward prevention, rather than toward chemotherapy and a cure. Palliative treatment became palliative chemotherapy—not to cure, but to relieve symptoms.

Authors like Jonas (2002) say biomedicine has made tremendous advancements, however, they come with the price of depersonalization of patients and care, increasing the costs of treatment and failure to maintain a holistic perspective. While the cure may be mastered, there are detrimental effects. He distinguishes between the use of alternative (instead of conventional/traditional) treatment, complementary (alternative

medicine used to supplement conventional medicine) treatment and integrated (used in a coordinated fashion with conventional medicine) treatment, arguing for the integrated model. For improved health/health care, we should seek out and support the integration of: early detection methods, low-cost technology-based approaches, low-cost CAM approaches and methods with low profit potential such as over the counter, self-care methods. He also notes that it is biomedicine that generally defines what treatment is considered CAM.

What is CAM?

In a given year, 1/3 of Americans use CAM (Kessler et al 2001) and, in 2002, approximately 62% of adults in the United States, approximately 123 million people, reported the use of some type of CAM. (Saydah and Eberhardt 2002) CAM, or Complementary Alternative Medicine, has been described as fluid or unfixed (Goldstein 2008) and context sensitive, varying based on historical and cultural factors (Broom and Tovey 2007, Broom and Tovey 2008), encompassing many nontraditional methods of treatment, depending on who, when or where 'traditional medicine' is being defined. (Goldstein 2008) According to Frohock (2002) "CAM today in the West occupies no sharp and distinctive category. There are instead continuums of various slopes and lengths on which types of complementary and alternative medicine are arrayed." (583) Braun et al (2007) points out that the comparison of studies of CAM use over time is contingent on definitions of CAT and medical education remaining static, which they, by definition, do not. Goldstein (2008) argues that the variation in use/likelihood of use of CAM across studies is related to lack of consistency in how researchers define CAM.

Therefore, the use of a definition that accounts for these variations across time and cultures is critical and most studies use wording in their definitions that allow for that flexibility, along with the idea that these practices "complement mainstream medicine by contributing to a common whole and satisfying a demand not yet met by orthodoxy or diversifying the conceptual frameworks of medicine." (Balneaves et al 2007: 973) (Goldstein 2008, Frohock 2002, Broom and Tovey 2007, Broom and Tovey 2008, Saydah and Eberhardt 2006, Braun et al 2007, Balneaves et al 2007, Kessler et al 2001).One definition that is repeatedly used and cited by other researchers seems to resonate nicely for the purposes of the current study. This definition from Broom and Tovey (2008) states:

> "There is, in fact, no clear definition as to what CAM is or indeed a concrete (and static) understanding as to what differentiates CAM from biomedicine. In saying this, CAM is generally used to refer to a diverse and often paradigmatically disparate range of therapeutic practices including (but not limited to): aromatherapy, naturopathy, herbalism, homeopathy, reiki, acupuncture, spiritual healing, etc. What largely characterizes CAMs is, first, a lack of integration into western healthcare systems and, second, their tendency to espouse models of care that incorporate (or at least give reference to) physical and metaphysical elements in treatment processes." (p141-42)

Balneaves et al (2007) include biological, physical, psychological, energetic, and spiritual therapies in their definition of CAM (974) and Saydah and Eberhardt (2006) elaborate on the particular types of practices and group them into 4 slightly different categories: biological, which includes herbs, special diets, and vitamins; alternative medical systems built on systems of theory and practice, including acupuncture and ayurveda; mind-body medicine which uses techniques to enhance the mind's ability to affect body function and systems and includes biofeedback, meditation, guided imagery,

and prayer for health reasons; and manipulative-based practices, those that are based on movement of one or more body parts such as chiropractic or massage.

Beyond the specifics of various treatments encompassed in CAM, researchers state that the view of CAM should not be restricted to supplements or particular therapies but also include the core beliefs that underlie these particular therapies. Goldstein (2008) postulates that the appeal of CAM to its users comes from its 5 core beliefs. Those core beliefs consist of holism, vitalism, spirituality, a positive definition of health and a distinctive view of the healing process.

Holism is the belief that the whole is greater than the sum of its parts. The goals of the treatment, which treatment is chosen and the outcomes of the treatment all depend on the individual's "unique constellation of body and mind, along with the environment (social and physical) he/she inhabits." (4) In other words, the emphasis is on what distinguishes this patient from others who are similar, both in illness, chosen treatment and the outcome of the treatment that is utilized.

Vitalism is the belief that a life force promotes health and healing. This force acts by filling the body with a flow of energy. Illness is typically understood as some sort of impeding force, getting in the way of the life force or flow of energy. The body reflects one's physical and social environment and disease is a "pattern of disharmony" in those elements. (6) Successful therapy removes the impeding force, restoring order in the energy flow and reestablishing that harmony, rather than eradicating disease. Specific treatments that would fall under the umbrella of vitalism are chiropractic, qi gong, Ayurveda and acupuncture.

Goldstein (2008) defines the core belief of spirituality as a strong emphasis on the role of spirituality in protecting against illness and fostering recovery and says that, for many patients, this is one of CAMs most attractive features. Goldstein emphasizes that oncologists, as well as other physicians, should be aware that spirituality plays a multifaceted role in the way CAM's approaches deal with health and illness. It not only offers motivation for trying to remain healthy and fight symptoms, but also offers specific guidance on practices (i.e. meditation and prayer) that can help a person with cancer achieve a healthy/healthier state. Spirituality can not only motivate healthy practices, but be an outcome of healthy practices.

Another one of CAM's core beliefs is a positive definition of health. According to this belief, rather than the absence of symptoms or sickness, health is a positive goal to be gained through effort. It is in this way that he says "CAM offers the lesson of seeking the meaning of health independently of symptoms and disease." (8)

Finally, CAM has a distinctive view of the healing process. Conventional practitioners make healing synonymous with the removal of pathology and symptoms while CAM emphasizes taking responsibility for healing. Curing always entails a commitment on the individual's part and is an active process, not a passive one—also referred to as proactive versus reactive by Mackenzie et al (1999). A person need not necessarily accept responsibility for being ill in the first place, but, regardless of how an illness has come about, a cure can occur only if the person accepts the reality of being ill and the responsibility of dealing with it. Symptoms are viewed as a message to be understood and responded to in personal terms rather than as an enemy needing to be

destroyed by medicine or removed via surgery. CAM views caring as an important role of the healer, who, under the umbrella of this core belief, see their role as helping sufferers decipher the meaning of their illness or symptoms in terms of interaction between body, mind and spirit.

Sources of treatment knowledge

Worsley (1989) categorized sources of health information into 3 groups: formal sources, informal sources, and commercial and media sources. Formal sources include health care providers and information provided by those providers, whether expert opinion and advice or formal pamphlets and literature. Informal sources are friends, relatives and social networks and the advice they might provide via recommendation and word of mouth. Commercial and media sources consist of TV commercials, magazine and newspaper articles, etc. and the information gleaned from them. Preferences for utilizing these types of health information sources vary widely by context and personal characteristics. In Montague's 2010 examination of pregnant women's source of learning health information, all 3 sources of health information were utilized by patients. Physicians and health care providers spoke to women, themselves and provided information via booklets and pamphlets. However, women felt like they had to pry their physicians for information and that they were largely unavailable until the time of childbirth, so they went out on their own and utilized social and media sources for the vast majority of their information. They preferred formal sources, in the form of direct contact with their doctor, but in light of a lack of access to their physician, sought out commercial and media sources. Physicians and health care staff felt that providing the

pamphlets would "reduce the workload for nurses and other care providers and reduce the likelihood that patients would fail to receive education," (Montague 2010: 1309) but it would seem that this substitution does not satisfy the need for the personal connection and human interaction that patients desire in obtaining information from formal sources.

When it comes to accessing CAM treatment or information, studies reveal that knowledge gained through social networks (informal sources) is more influential than the impersonal media (commercial and media sources) to those that are ill. (Kelner and Wellman 1997) According to Broom and Tovey (2007), people feel that science cannot predict what happens to them or their bodies. A substantial number of patients, regardless of CAM use, had ambivalent, if not negative feelings toward statistics for survival or success rates of any type of treatment, whether traditional or nontraditional. In their interviews with 80 cancer patients, ages 20-87, where all major cancer types and stages of cancer were represented, Broom and Tovey (2007) found that patients feel that such probabilities do not tell people about how they, individually, will react to treatment or their chances of survival. Those individuals who do utilize the internet or other media for information are very particular about the websites they visit and sources of information along with the information they receive and tend to be suspicious of both CAM and biomedical information, questioning cure rates by biomedicine and the claims that CAM makes. (Broom and Tovey 2008) In fact, in a study of internet usage by parents of pediatric cancer patients utilizing traditional treatment methods, Gage and Panagakis (2012) found that parents deemed medically related cancer information on the internet untrustworthy and frightening, so much so that they actually avoided online

information seeking for fear of what they might find out, uncertainty about the accuracy of that information online, being overloaded by the volume of information and even being explicitly told not to go online by their children's oncologists. These individuals preferred to receive information related to diagnosis, prognosis and treatment options from a trusted healthcare provider (formal sources), rather than through the internet (media and commercial sources). Patients and caregivers alike have been found to have similar feelings regarding information on the internet. (Olson 2011)

Social networks exert an influence on almost all aspects of health and related help seeking for all individuals, from the illness experience to utilizing treatment and lay referrals. (Unger-Saldana et al 2011) Individuals who utilize CAM tend to get information and referrals for treatment and practitioners from individuals in their social network (informal sources) who have past experience with their particular disease or have utilized a particular treatment (Kelner and Wellman 1997, Tovey and Broom 2007, Van Kleffens et al 2004) or from friends and family (Tovey and Broom 2007, Van Kleffens et al 2004). In fact, in their 1997 study of individuals who utilize CAM, Kelner and Wellman found that one third of those individuals chose to use alternative treatments because they were suggested by others who it helped. The preference for utilizing social networks for health information is not limited to CAM users, however, and who uses which resources to find said information can vary, based on context and demographic characteristics.

A study comparing health information seeking between men with prostate cancer and women with breast cancer found that men were more likely to seek information on

the internet, with concerns centered around treatment information, medical personnel and procedures, while women were more likely to seek social and emotional support with more holistic (meaning overall health and wellness) concerns. (Seale et al 2006) Kakai et al (2003) interviewed 140 cancer patients to examine the differences between health information seeking among different ethnic groups in Hawaii and found that Caucasian patients preferred objective, scientific, up to date information obtained through medical journals or newsletters from research institutions and the internet (formal and media sources); Japanese patients relied on media and commercial sources including television, newspapers, books, magazines and CAM providers; and non-Japanese Asians and Pacific Islanders used information sources involving person to person communication with their physicians, social groups and other cancer patients (formal and informal sources). Although higher education stressed objective, scientific and current information and lower educational level was associated with more interpersonal information, the three ethnicity specific patterns remained relatively stable, regardless of education level, which, according to the authors, implies that the context of ethnicity overrides education in shaping choices of health information. This is indicative of the importance of recognizing cancer patient's culturally developed world views when understanding their health information seeking behavior and the need to eliminate cultural barriers facing cancer patients as they acquire health information.

Treatment decisions: making informed decisions

Patients heavily rely on their physicians to assist in making treatment decisions when the illness is life threatening. In a study of 100 patients, Siminoff found that 80%

accepted their physician's primary treatment recommendation. However, 20% still opted to disregard the physician's treatment advice. Using behavioral decision making theory, he identified 2 sets of factors in this outcome: those related to the amount and specificity of the information about treatments conveyed to the patients and the strength of the treatment recommendation itself. The patients who didn't accept the treatment recommendation were told more specifically what the benefits would be and rated the side effects of treatment to be more probable and severe than those who concurred. In this way, this study supports findings of others that patients want more specific disease and treatment information in order to make treatment decisions--however, providing it may lead to treatment decisions that diverge from physician recommendations. (Siminoff 1991)

According to Gaston et al's (2005) systematic review of the literature on decision making and information provision in patients with advanced cancer, health professionals often fear that giving patients more information will increase anxiety levels, much like the oncologists of pediatric cancer patients who discourage parents from seeking information on the internet with the same reasoning (Gage and Panagakis 2012). However, research does not support this fear as legitimate. Being informed, in and of itself, seems to help maintain a sense of control for patients and is an important part of utilizing problem focused coping in the face of the stress of making decisions about how to treat cancer. (Gaston et al 2005) "Patients with advanced, non-curable cancer face difficult decisions on further treatment, where a small increase in survival time must be balanced against toxicity of the treatment. If patients wish to be involved in these

decisions, in keeping with current notions of autonomy and empowerment, they also require being adequately informed on treatments proposed and their own disease and prognosis." (2258)

The social context of treatment decisions

Health decision making is a very complex series of actions that are effected by an individual's life circumstances, and heavily influenced by family, cultural, and both local and national contexts. (Davidson et al 1992) Fatalism, a belief in a lack of personal power or control over destiny or fate, has been held as a major barrier to participation in positive health behaviors and, as such, has been seen as having negative impacts on treatment. However, this personal belief system is more prominent in poor and less educated populations and Drew and Schoenberg's (2011) analyses of two in-depth ethnographic studies of rural women's health decisions surrounding cancer treatments suggest that inadequate access to health services, a legacy of self-reliance and insufficient privacy all lend themselves to a culturally acceptable ideal of fatalism. Though these women seemed to have fatalistic ideas regarding cancer and its treatment, as a population with fewer resources, they were more likely to take steps such as delaying treatment because of a lack of financial resources at the time, delaying treatment to financially prepare for the possibility of bad news and taking measures that were seen as extreme and not yet necessary, such as full hysterectomy, because it was the only guaranteed and most immediate solution. Taken together, these women's illness narratives reveal attempts at agency despite constrained choices, and demonstrate the

importance of considering context, rather than one isolated psychological construct, fatalism. (Drew and Shoenberg 2011)

Similarly, in Radley and Payne's (2009) sociological exploration of why patients decline treatment for cancer, the authors found that such a decision, though it might seem to be defiant and/or self-driven on the surface, is actually a highly social act. To opt out of treatment is to turn away from one of the obligations of the sick role, which is to seek medical advice and take it. Because patient choice takes place within an advisory context set by doctors, it should be understood in relation to opportunities afforded by the particular clinic in question. If there are multiple providers, the patient may be given conflicting signals about the best course of action. Beyond the clinical setting, patients who refuse treatment say that their decisions were influenced by their personal experiences and values or those of close others, rather than being influenced by information from the doctor. In fact, these patient's roles and involvement in other groups that would be impacted by negative effects of the treatment are part of what weighs in on the decision to refuse treatment. (Radley and Payne 2009)

Even when significant others are not physically present during the process of making decisions about treatment, patients still carry the thoughts and concerns of others and their responsibilities in those relationships and roles into the interaction, effectively making it what Forsyth et al (2011) refers to as a "crowded room."

Although shared decision making is conceptualized as an interaction between patients and doctors in the clinic, decision making occurs over a longer period of time than simply in the consultation, which implicates a larger context of patient experiences

and relationships. Therefore, any discussion of patient decisions to undergo treatment must be viewed in relation to the social institutions and individuals that impact their daily lives. (Forsyth et al 2011) Beyond that, patient values and preferences are dynamic, rather than static and evolve over the course of illness as a result of changes in knowledge and understanding of the illness, as well as the course of the illness trajectory. While a patient may start out as a passive decision maker, accepting whatever the doctor tells them as they are the expert, they may later make decisions about treatment for the sake of others, in order to survive and be with them. Physicians in Forsythe et al's (2011) study said that there were times patients didn't want a transplant or particular treatment, but they went through with it because their family did. Likewise, in Radley and Payne's (2009) study, patients who were married did not refuse treatment, while those who were single did, which may be indicative of the same sense of fulfilling social roles and taking other's wishes into account.

At times, significant others may take a much more active role in the decision making process and actually be in the room, as evidenced by the results of Ohlen et al's (2006) study exploring how significant others were involved in cancer patient's decision making processes related to CAM use. Four main types of decisional involvement were discovered, including: creating a safe place for the patient to make a decision (helping to provide patients with the space they needed to make a choice that made sense to themselves and sometimes assisting in gathering and reviewing information about CAM treatments without disclosing their opinions); becoming a team (working together and respectfully sharing beliefs and preferences about CAM treatments); moving the patient

towards a decision (attempting to directly influence the CAM decision making process by encouraging patients to make a particular decision, motivated by a need to protect patients from harm); and making the decision for the patient (decisions were made based on personal beliefs, preferences and knowledge; occurred both with and without approval of patients because they were unwilling to wait for the patient to make a decision; and at times caused a conflict between the two individuals). Much like the progression of a patient's preferences over the course of illness, the ways that these significant others were involved in the process of treatment decision making evolved throughout the patient's cancer journey whether because of a negative outcome from CAM use, their own knowledge and experience related to CAM or their search to find a comfortable role of involvement. (Ohlen et al 2006)

The debate over patient versus physician choice in treatment decision

The relationship between doctor and patient is very complex. Patients have varying expectations of the degree of control they have over their choice of cancer therapies. Some want to collaborate with the physician in the decision making process, while others want to rely solely on the expertise of the physician and be told what to do. Some may make their own decision, but want the sanction of their physician for their choice. (Mackenzie et al 1999) While physicians have traditionally been an unquestioned source of knowledge in the past, the advent of the consumer mentality of health, the ability to access health information via the internet and a growing distrust in the medical system have led some patients to question the authority and motivation of their doctors in treatment decisions (Lupton 1997). In a study of 60 lay people with

various backgrounds. Lupton (1997) found that both the ideal-type "consumerist" (the patient who acts in a calculated manner to engage in self-improvement while being skeptical of expert knowledge) and the "passive patient" (one who defers to the physician's decision and does not question it) role are taken, sometimes even simultaneously, as dictated by context. For instance, being more proactive about the care one receives is easier to do and accomplish if one has the financial resources, as well as the social connections and knowledge of the healthcare system (Sinding et al 2010, Drew and Schoenberg 2011,) and active decision making has been found to be more common in patients with certain types of cancers (breast) than others (prostate). (Gaston et al 2005).

However, despite the fact that almost all patients expressed a desire for full information from their physicians, in Gaston et al's (2005) study, only 2/3 wished to participate actively in decision making and, in Lupton's (1997) study, it was determined that, when it comes to treatment decisions, people often want to be told what to do, not given the odds for each possible choice. Mendick et al (2010) studied treatment decisions from three different perspectives, simultaneously: observing consultations and exploring patients and doctors perspectives on these, audio recorded post-operative consultations in which further treatment was discussed, and then separately interviewed each patient and their surgeon within 7 days of the consult to explore their perspectives on the decisions that had been made. The study found that surgeons made most decisions for patients and only explicitly offered choices where treatment options were equivocal. Surgeons offered the treatment they felt was most appropriate for

maximizing survival and felt this was their responsibility, though they rarely took individual responsibility for the decision, utilizing words such as “we,” rather than “I.” Despite the fact that shared decision making was absent, patients still felt ownership of the decisions made for them by surgeons because they knew they could refuse. When comparing patient and physician perspectives in making decisions about treatment, patients felt they made decisions, while physicians felt they had more or less made them and, in fact, they told interviewers that, even when they offered choices, they retained control by choosing which options to offer and which options not to offer. When faced with choice, patients generally lacked trust in their own decisions and usually sought the surgeon's guidance. Being told what to expect inspired confidence and these patients felt that the questioning of surgeons was unnecessary.

However, other research shows that treatment outcomes may be improved if patients perceive greater control over their treatment. (Legg et al 1992, Deadmen et al 2001) People who believe that events are under their own control generally have better health and attain better outcomes than those with contrary beliefs (such as the previously discussed Fatalism) following various treatment programs. (Legg et al 1992, Drew and Schoenberg 2011) Legg et al (1992) investigated responses of patients in a cardiovascular risk management clinic when they were invited to make a decision about their treatment. While the ownership of decisions was not usually attributed solely to themselves—patients saw "other people" as being involved in making the decision, while they had the dominant role--they perceived a high degree of responsibility for the decision and it’s consequences. Even when the individual's involvement in a decision

made no difference as to what treatment they received, people who could attribute the choice of treatment to themselves responded more favorably to treatment than those who could not. (There was no significant relationship to sex, age, marital status or educational level and employment) (Legg et al 1992) Similarly, Deadmen et al (2001) distinguished between 2 separate but interrelated components for decisional control: having direct informational input into the decision making process so that the patient receives their preferred treatment and feels their wishes are being taken into account and taking personal responsibility for the treatment decision that is made. They found that breast cancer patients who chose their own treatment fared better psychologically and had more positive outcomes with treatment. Beyond that, those who took explicit responsibility for that choice fared even better. (Deadmen at al 2001)

Turning to CAM

A great deal of research attempts to shed some light on the idea that people either seek alternative treatment because traditional medicine has not resolved their health problems (Kelner and Wellman 1997, Lupton 1997, Mackenzie et al 1999) or because they are convinced that it is a better form of treatment for them, personally. (Kelner and Wellman 1997) Saydah and Eberhardt (2006) reviewed the theories for why CAM is utilized and found 3 main themes: the need for personal control in health care decisions, the desire for personal congruence of treatments with worldview and values, and dissatisfaction with conventional treatments. I examine each of those themes separately.

Desire for personal congruence of treatments with world view and values

As Goldstein (2008) mentioned, the basic tenets of CAM are appealing to many individuals because they fall in line with their own personal belief systems. They allow patients to take into account spirituality and craft a plan of care that aligns with their ideals about their bodies and health. According to Frohock (2002), the turn to CAM may represent a chronic (and, to some, welcome) inclination of the human intellect to delimit the energies of material inquiries with metaphysical baselines and options. (583) The 5th core value of CAM mentioned by Goldstein (2008)—a distinctive view of the healing process—not only emphasizes this connection between mind and body in healing, health and illness, but also places an emphasis on personal responsibility in acceptance of being sick and treating the illness, itself. Indeed, the desire to not be passive in treatment and healing comes up repeatedly as a reason people seek alternative methods of treatment. (Mackenzie et al 1999, Tovey and Broom 2007, Van Kleffens et al 2004)

Despite the roots of CAM in other cultures, the beliefs that underlie these therapies are also a part of American culture. "An emphasis on individualism, personal responsibility, freedom to choose, and transcendence all go back to the values espoused by America's founders. (Goldstein 2008: 10) The alignment of these two sets of values causes CAM to resonate with many Americans.

Taking control

This idea of personal responsibility is closely related to taking control of one's health. Studies have shown that people who desire to keep control of their health care in

their own hands are more likely to use alternative medicine. (Braun et al 2007, Kelner and Wellman 1997, Mackenzie et al 1999) CAM creates perceived increases in feelings of control, power and individual autonomy within therapeutic processes (Broom 2009: 71) In a study that compared a group utilizing alternative treatments and a group utilizing a family doctor, Kelner and Wellman (1997) asked participants who they thought could help most with their health problems and the group utilizing alternative treatments made it clear that they relied primarily on themselves for helping, with over 1/3 saying that they believed they alone would be most helpful and another fifth declaring that they, in partnership with their practitioner, could help most with their health problems, demonstrating not only the alignment of their beliefs to those espoused by CAM therapies, but also that alternative medicine users seem to believe that they are (and desire to be) more in control of their own health.. In contrast, the group utilizing the family doctor said that their physician could help them the most. These values of self-reliance are also in alignment with American culture. (Goldstein 2008) In American society, health is a commodity and being a smart consumer of health information, goods and services is encouraged, largely by the "extensive and consuming interest in the body that characterizes Western society." (Kelner and Wellman 1997: 211-212) People are inundated with images and ideas that remind them of the human condition of mortality and the inevitability of deterioration and, ultimately, death. They are simultaneously reminded that there are measures that can be taken to personally prolong life and minimize deterioration. As a result of the increasing number of private and public testimonials about various alternatives to achieve this, more people are

exploring these alternatives as a way to cope with their particular health problems. (Kelner and Wellman 1997) People gain their information from a multitude of sources including friends and family, other people struggling with similar health concerns, mainstream media and the internet. According to Broom and Tovey (2008), the internet-informed patient has been conceptualized as a part of the wider departure from the traditional Parsonian sick role to a more consumer-orientated, active role whereby patients are able to question professional advice-giving; a process that can influence patient roles and clinical autonomy. (143) As people shift into the role of "concerned consumer," "rather than relying on institutional legitimacy as the basis for selecting alternative care," (Kelner and Wellman 1997: 211) we begin to see questioning of the medical system and, in some cases, an attempt to find a resolution for it's perceived shortcomings in individual instances.

Dissatisfaction with conventional care

As Kelner and Wellman (1997) point out, literature from the medical sphere argues that CAM is only chosen when people are unable to find help for medical problems from conventional services. Meanwhile, alternative medicine studies argue that patients are pushed toward CAM because of negative past experiences with traditional medicine, rather than their belief in alternative therapies. Indeed, interviews of current CAM patients have produced a recurring theme of distrust of the medical system based on past negative experience with disease or treatment, either experienced themselves or shared with them via others. (Katapodi et al 2010, Lupton 1997, Radley and Payne 2009, Wainer et al 2012, Mackenzie et al 1999, Tovey and Broom 2007, Van

Kleffens et al 2004) Dissatisfaction with conventional medicine (along with health aware behaviors) was the best predictor of CAM use in a study of CAM and conventional medicine users by Sirois and Gick (2008) and Saydah and Eberhart (2006) mention that CAM is often used because, monetarily, there is difficulty obtaining biomedical care. Trust of physicians can be negatively impacted by the belief that conventional therapy is profit driven (Mackenzie et al 1999) in conjunction with the rise in malpractice suits and physician errors over the last several years. (Lupton 1997)

Goldstein (2008) points out that a great deal of CAM's appeal is the fact that it is a response to the perceived flaws in our health care system. Along with the increased consumer marketing of CAM and the appeal of a natural solution, the lack of success in treatment of some areas of allopathic medicine and its lack of attention to patients have caused an increase in the use of CAM. (Frohock 2002) In addition, the use of CAM fulfills psychosocial needs that are inadequately addressed by the biomedical system, such as managing side effects and reducing pain and anxiety. (Jones and Denmark-Wahnefreid 2007, Wainer et al 2012) In Hok et al's (2007) examination of the personal narrative of a patient who used both traditional and nontraditional treatment in their fight against cancer, the patient disclosed to their medical physician the idea that they were considering using an alternative treatment method in the face of not having any other treatment suggestions from that physician. The physician's response is one of a complete lack of interest, which only intensified the feeling of the patient, and indeed one expressed by many patients in the literature (Braun et al 2007, Broom 2009, Frohock 2002, Kelner and Wellman 1997, Goldstein 2008, Jonas 2002, Jones and Denmark-

Wahnefreid 2007, Mackenzie et al 1999, Saydah and Eberhardt 2006, Tovey and Broom 2007, Van Kleffens et al 2004), that the physician is not invested in the patient as a person, in stark contrast to their experience with their CAM physician. CAM, on the other hand, views caring as an important role of the healer (Goldstein 2008) and CAM practitioners often play a critical role in ensuring patients maintain hope and in the face of an undesirable prognosis (Broom and Tovey 2007)

Broom and Tovey (2007) argue that, rather than reflecting broad paradigmatic change, the increasing presence of CAM in cancer care should be characterized as a dialectical tension between therapeutic processes engendering individuation (agency, self-responsibility, wellbeing, individual healing) and depersonalization (cure rates, probabilities, abstraction). Moreover, the ways in which patients attempt to manage this dialectic are deeply embedded in the nature of their disease (disease stage and prognosis) and their age.(1027) Patients tendency to critically assess biomedical assessments of their conditions were contingent upon the odds they were given and how acceptable they felt these were--the more ambiguous or negative, the more statistics were viewed as unable to predict. The degree to which the prognosis was acceptable seemed to be mediated by age—where younger patients tended to have more difficulty accepting their prognosis than older patients who might be more comfortable with the idea of their lives coming to a "natural end". (Broom and Tovey 2007) Because of their fear of exposure to these impersonal, biomedically defined cure rates that, from their perspective, would hinder a potential healing process, patients of CAM went so far as to avoid ongoing use of the internet, altogether. (Broom and Tovey 2008) Van Kleffens et al (2004) sought to

clarify how the concept of patient autonomy can be applied to situations where patients don't just avoid statistics, but actually refuse a recommended oncological treatment. In their interviews with 30 cancer patients and 16 physicians, they found that those decisions do not so much rely on the medical information about disease and treatment options, but are rather inspired by patients' own experiences or those of close others. The extent of pressure physicians exert to persuade the patient to be treated as recommended depends on the medical distinction between a curative and a non-curative treatment goal, but that pressure does have an effect on patients' experiences of being free or of having a choice in their treatment decisions. (Van Kleffens et al 2004)

Dissatisfaction with CAM

Despite the arguments for CAM and the obvious ways that it provides answers to the shortcomings of conventional medicine, alternative therapies are not without flaw. Practitioners articulate holistic philosophies that describe healing as open-ended with correspondingly expansive definitions of what it means to be healed, rarely articulating clear ways of conceptualizing or measuring the efficacy of their own treatments. (Sered and Agigian2008: 617) Similarly, in one of Broom's studies (2009), CAM users indicated that they had some problematic experiences with clinicians involving erroneous diagnoses or highly restrictive diets with little information entailing how or why they worked.

An equally troubling trend for those who utilize alternative treatments is the feeling of pressure to meet the ideal of responsibility for their health, which sometimes includes taking responsibility for being sick in the first place and places what some

patients perceive to be an unrealistic expectation on them for the state of their health as well as behaviors to maximize it. (Broom 2009, Mackenzie et al 1999) For example, CAM practitioners redefine their patient's breast cancer diagnoses in ways that expand and transform their illness, sometimes into a lifetime journey. In interviews with 46 Boston area CAM therapists treating breast cancer patients, researchers found that practitioners help give meaning to the cancer and speak about breast cancer as a symptom of problems that exceed the cancer itself, at times suggesting that the women are responsible for their own breast cancer. (Sered and Agigian 2008: 617) Other studies have highlighted the fact that one of the basic tenets of CAM—that patients are responsible for their own health—while intended to be an overarching belief and distinguishing characteristic of CAM that its proponents specifically find to be appealing because it supports the idea that people are in control of their own health, still allows for and at times encourages this over acceptance of the burden of responsibility, thereby making this feeling of personal pressure to rectify the state of one's health possible. (Kelner and Wellman 1997, Broom 2009)

Who uses which treatment options?

In a comparison between elderly patients of conventional health care and elderly patients of alternative medicine, Wellman et al (2001), in accordance with previous research, found that CAM users are typically more affluent, white females with higher education (Braun et al 2000, Wellman et al 2001). Many sought alternative treatment when they had exhausted traditional options, but others went directly to it because of past experience with it or because they had a different philosophy about the nature of

health and healing from the one advocated by traditional medicine and were uneasy with surgery and the use of drugs. However, most of these elderly patients utilized a family physician and traditional medicine. These patients tended to explain decisions about care in terms of trust and belief in their doctors authority and expert skills. While family physician patient's pathways to care are characterized by many different types of medical care, typical alternative pathways to care are characterized by a combination of medical and alternative use where several kinds of therapies and practitioners are utilized until one satisfies their needs. Both groups said that the most important influence in selecting a practitioner was the referrals of friends, family and coworkers. Not surprisingly, when asked who they thought could help most with their health care problems, the family physician patients stated the physician would be most helpful and the alternative patients replied that it would be themselves, perhaps in conjunction with a practitioner. Because the population being interviewed is older adults, the findings of this study may reflect the context of a generation that grew up believing in the power of scientific medicine and the authority of experts such as physicians. This may explain the tendency for younger adults, who have been more influenced by the trend of patients as health care consumers, to be more open to alternative treatments and may reflect a shift in future studies of older adults (Wellman et al 2001).

Kelner and Wellman (1997), in accounting for predisposing factors for CAM use, found that those utilizing CAM were more likely to: be female, urban residents, younger, married, more highly educated, have higher lever occupations, have fulltime employments, high income, more likely to report ethnic origin as Canadian the study

was based on Canadian respondents), and have no religious affiliation, but say that they consider spirituality to be an important factor in their lives. Overall, Sirois and Gick (2008) found that income was a significant discriminator against CAM use, but did not predict initial or continued use. Rather, openness to new experience was associated with CAM use in general, was most notable in the decision to initially try or explore it.

Simultaneously, a study of the use of CAM to treat anxiety and severe depression by Kessler et al (2001), found none of the sociodemographic variables (gender, education, age, income, race, marital status, employment status, region of the country and urbanicity) had significant effects on rates of or likelihood to use CAM. However, adults with no chronic diseases are least likely to report use of CAM (Saydah and Eberhardt 2006) and, similarly, Kelner and Wellman (1997) found that most people consulting alternative practitioners were seeking care for chronic ailments. Adults with chronic diseases are more likely to be older, female, and non-Hispanic white (Saydah and Eberhardt 2006), which falls in line with characteristics noted as typical of CAM users by aforementioned studies. Still, inconsistencies with findings, suggest that, as noted by Sirois and Gick (2008), CAM patients should not be examined as a homogenous group. As Wellman et al (2001) phrased it, "it is clear that the choice of alternative therapy cannot be accounted for without understanding the meaning such a therapy has for the individual user." (19) It also seems important to consider the distinction between those with chronic illness and those without should be made when examining demographic and socioeconomic variables of those who utilize CAM should also be made.

Studies have shown that the decision to use CAM usually takes place early in a patient's journey toward wellness/illness eradication—6-12 months after diagnosis. This particular study indicated that those in the early stage of disease were recruited because previous research has shown that decisions about CAM most frequently take place during this period of breast cancer trajectory (6-12 months from initial diagnosis). (Balneaves et al 2007) This brings attention to the idea that even the stage of illness or treatment can have an effect on the results of a study over CAM users. Beyond that, the particular illness may have implications for the likelihood of CAM use as well.

Saydah and Eberhardt (2006) used the 2002 National Health Interview Survey to determine how likely adults with chronic diseases were to use CAM and found that they were more likely to use them than others. People with cancer were found to be the 2nd most likely to use CAM at 55% While the role of CAM in oncology is consistent with most other areas in medicine, the core beliefs of CAM are well-matched to the way that many cancer patients experience their bodies and sickness. CAM therapies form a response to difficulties many cancer patients have when dealing with conventional medicine, including the lack of attention to mind-body issues and environmental causes of cancer, emphasis on treatment at the expense of prevention, and general concerns about the health care system. (Goldstein 2008)

Problems with the antagonism between CAM and traditional medicine

Patients experience a feeling of frustration over the sense of conflict between CAM and traditional physicians. (Balneaves et al 2007) This dynamic between CAM and traditional medicine can be problematic when their differences cause patients to not

fully disclose the use of treatments from the other realm (mostly CAM to Biomedical, but also vice versa).

Complementary and alternative therapies are used more than conventional treatment by people with self-defined anxiety attacks and severe depression, likely due in part to the stigma attached to mental illness and resulting avoidance of visiting mental health providers. Most patients that do visit conventional mental health providers for these problems also use complementary and alternative therapies--use that will likely increase as coverage expands—but often do not disclose the use of these treatments. (Kessler et al 2001) Balneaves (2007) also found that 50% of the women in their study, who had breast cancer, chose not to disclose their use of alternative therapies to their physicians and Cincotta (2006), in a study of CAM use among 500 children in pediatric hospitals--1 in Cardiff, and 1 in Melborne (UK and Australia)—found that there was a lack of disclosure of CAM to medical practitioners in both Cardiff and Melborne groups.

According to the results of Frohock's 2002 study, physicians often don't even ask patients if they are using CAM, which can be problematic because of interaction effects with medicine. Some examples of CAM therapies that can react adversely with medical treatments are aspirin therapy or diuretics, conventional diabetes treatment via blood glucose levels, and antidepressants or other anxiety/depression medications. (Jones and Denmark-Wahnefreid 2007, Kessler et al 2001, Saydah and Eberhardt 2006) Asking patients about their use of these treatments could prevent adverse effects (reactions between pharmocotherapy and herbal treatments, etc.) and maximize the usefulness of therapies subsequently proven to be effective, so communication is

important.(Kessler et al 2001, Hok et al 2007, Jones and Denmark-Wahnefreid 2007, Saydah and Eberhardt 2006, Smithson et al 2012) As Smithson et al (2012) found in their content analysis of 26 published qualitative studies of cancer patients experiences of complementary therapies, the most notable barrier for the use of CAM in patients with chronic illness was the perceived polarization of complementary therapies and biomedicine. Clinicians in alternative treatment centers often hear from patients, family members and physicians about difficulties that arise when patient/physician discussion and expectations about complementary therapies are incongruent and misunderstood. This polarization between complementary and conventional medicine can affect patient interaction and increase potential for miscommunication, which is exacerbated by the stressors of a life-threatening illness. (Mackenzie et al 1999) It is no surprise that patients report better experiences in integrated settings, where complementary and biomedical treatments coexist.(Smithson et al 2012)

Conflict resolution

These contrasts between traditional or biomedical treatments and complementary alternative treatments seem to be answering to the short-comings of one another, but their being at odds causes problems for the people who are need of the benefits the treatments would provide the most. Tillman (2002) reviewed empirical studies of third-party coverage of CAM and the factors behind the reluctance of health insurers to provide benefits for those treatments. Reluctance is based on three factors: a lack of scientific evidence supporting CAM providers' claims of medical efficacy, the absence

of standards of credentials for many CAM providers, and difficulties in fitting CAM treatments into typological schemes that determine levels of reimbursement. (583)

Despite their starting point that CAM is not usually accepted by conventional medicine, some elements of conventional medicine are increasingly accepting of CAM (Goldstein 2008) and some medical schools also now offer basic education in CAM (Braun et al 2007). Beyond the institution of the medical system, ways of thinking about medicine and nontraditional treatments have also started to change as "new age conceptions of healing have spread and that constellation of attitudes encourages people to look beyond conventional medical care and make their own judgments about which types of therapies are most suitable for their problems." (Kelner and Wellman 1997: 204 In Broom and Tovey's (2007) study of cancer patients, they found that a significant number of patients not only prioritized experiential knowledge and rejected the need for scientific evidence, but also judged particular treatments on their effects, rather than the reputation of the practice itself.

In spite of their differences, boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed. (Goldstein 2008) Kelner and Wellman (1997) conducted interviews with 300 patients, 60 from each type of physician/practice: family physician, chiropractors, acupuncturists/traditional Chinese doctors, naturopaths and Reiki practitioners to help explain why people chose orthodox medicine or an alternative type of care. After taking into account the nature and duration of illness and predisposing factors of age, gender, educational level and health beliefs, they found that the choice of type of practitioners is multidimensional and

cannot solely be explained by either disenchantment with medicine or by an "alternative ideology." (203) Additionally, in their study of individuals utilizing CAM to treat severe anxiety and depression, Kessler et al (2001) found no evidence for significant variation between the perceived helpfulness of complementary and alternative therapies on the basis of whether the respondent also used conventional therapy and vice versa. So we can see that the boundaries are starting to become a bit more unclear, even for those who are ill and would be skeptical consumers of medical information or solutions to health problems. Perhaps what is needed is, as Smithson et al (2012) suggested, an integrated approach, where patients can pick and choose the methods of treatments that most appeal to them. In the meantime, a worthy pursuit would be the clarification of the perceived short-comings of both biomedical and CAM treatments and the reasons that each has been chosen as a form of therapy. If these ideas can be illuminated, then we will be one step closer to a health system where more people are satisfied with their treatment and role in the process of becoming well, and physicians and practitioners can feel more like they are helping people, rather than a cog in the wheel of a system many people do not trust, regardless of which side of the biomedical/CAM debate they find themselves on.

CHAPTER III

RESEARCH METHODS AND DESIGN

Research questions

The literature suggests that cancer patients seek to be fully informed, have some degree of control over their treatment, clear communication and a good relationship with their physician, and a high probability of success in treatment. How do different treatment centers portray themselves to meet these desires? What information is most important to clients, and are there individual characteristics of clients that help predict which treatment center they will choose? How do physicians and staff meet the perceived needs of their clients and what level of priority does that take in delivering treatment? Do the needs of the clients and the desires of the medical personnel match?

Study design

This study design has two components. One is an analysis of the websites and documents provided by the two different types of practices (traditional and alternative) to ascertain how they portray themselves to audiences. I will be analyzing these for themes and images used in presentation. How do the centers portray not only themselves, but choices in treatment options? What is the role of the client, the center itself and the professionals at the center?

The second component is interviewing the staff at the centers. These staff include nurses, technicians, therapists, receptionists, practitioners and physicians. In these interviews, I ask how these professionals view their roles in providing information

and treatment. How are the clients viewed? How is the decision making process analyzed? What is the role of insurance in all of this?

I hoped to control on as many characteristics of these traditional and nontraditional treatment centers as possible so that the difference among them could be traced to their purpose rather than other factors such a location, and cultural context. To do this, I chose to consider both traditional and nontraditional medical facilities within the state of Texas. I began by choosing the "nontraditional" clinics. To classify them, I considered the following definitions:

Traditional Clinics are a) headed by a doctor who practices regularly at a hospital; b) have patients referred to them by their general physician or the doctor who discovers the cancerous cells c) invoke traditional medicine, especially chemotherapy and radiation.

Nontraditional Clinics do not have any of the characteristics mentioned above and self-identify as utilizing alternative medicine.

While content analysis of websites and interviews of practitioners are present in my study and analysis, they are different form from the original conception. Initially, I planned to do a case study of three centers that could be classified as traditional and three centers that could be classified as nontraditional. At each center, I would conduct in-depth interviews, starting with one respondent at each location and utilizing a snowball sample technique, where respondents referred me to other individuals like themselves.[1] However, I was unable to gain access to enough respondents using this method.[2]

Consequently, I resubmitted to the IRB to allow recruitment of respondents for interviews to come from clinics or facilities in the state of Texas and made changes to the proposed sites for content analysis. This change to recruitment allowed me to collect more interviews from a broader range of facility/practice types.. This created a total of 4 interviews from alternative practitioners and 6 interviews from traditional practitioners.

With respect to traditional treatment centers, adjusting the proposed sites for content analysis allowed me to accurately reflect the variety of facilities represented by the staff interviewed in this study.

With respect to alternative treatment centers, reservations from practitioners about their anonymity also made it extremely difficult to get potential respondents to consent.[3] As a result, some of the respondents came from larger treatment centers, but others were individual practitioners who had private practices. Obviously, to include only their websites in my content analysis would compromise their anonymity, so I utilized a public directory of alternative practitioners (www.cancure.org) for the state of Texas who are listed as treating cancer patients and included an analysis of a few of these websites to reflect the type of information portrayed for these types of treatment facilities since they are not the same as a large center would be.

The websites of 11 treatment centers, 4 traditional and 7 nontraditional, were examined for the content analysis portion of this study. Only 4 traditional treatment centers were examined due to the volume of materials on the websites. As will be discussed in detail later, these websites were very detailed and thoroughly covered every aspect of treatment and care and were thus very dense. Additionally, these centers were

chosen to represent the areas of the state where respondents came from, without sacrificing their anonymity. The 7 nontraditional treatment centers, like the traditional treatment centers, represent some sites where practitioners worked, but there are also those that do not, for the sake of anonymity. Very few alternative practitioners are willing to openly admit that they treat cancer patients (see endnote 3). As a result, I utilized a public registry of naturopathic physicians and examined all of the websites for those treatment centers that claimed to treat cancer in the state of Texas. Some of the sites in my analysis were not on that website, but they still have websites that claim to treat cancer and are large enough centers as to not threaten participant anonymity.

All sites were examined only in March 2016 to control for any changes or updates that might be made to these websites before or after their analysis. Atlas.ti was utilized to assist in the coding of both the written content of the websites as well as the images portrayed on those sites. Open coding was first done and word counts were utilized to see which words were repeated most often. The frequency of these repeated words led me to look for these particular words and images in the websites. As these patterns became apparent, families of codes were created and documents and images were grouped together, accordingly. Those families became the themes identified in the findings section of the content analysis.

The interviews lasted from 45 minutes to 3 hours, and were transcribed and those transcripts were examined, paying close attention to any patterns that arose in the responses across the sample of individuals interviewed. Respondents were asked questions about the branch of medicine they did not practice (their knowledge of this

branch of medicine, why they felt patients found it appealing), questions about their own branch of medicine (why they felt patients preferred their branch of medicine, their role in the treatment process), questions about the perceived effect of available health information on the internet on the relationship between doctors and patients, questions about whether or not they felt that the amount of trust in physicians had changed, questions regarding how much control patients should have and should *feel* that they have in the treatment process, and questions regarding the effect of insurance on the treatment process. Respondents were also given a vignette that followed a hypothetical patient through the process of a treatment recommendation being made, to this hypothetical patient choosing a treatment option that the practitioner did not necessarily feel was best. Questions were asked to ascertain what patients typically do in these situations, as well as how they feel in these situations in an effort to see if there is a disparity between the two and how this might affect the doctor-patient relationship. (see Appendix A for full interview guide)

Cancer represents a highly specific context in which the consumption of CAM has particular meanings--meanings that may be very different from those observed in other disease and health contexts and serves particular roles. (Broom and Tovey 2007) The core beliefs of CAM align with the way that many individuals with cancer experience illness and their bodies, as well as providing an answer to issues many of them experience with conventional medicine. (Goldstein 2008) In addition, the threat of terminal illness has considerable implications for patients' preparedness to extend beyond traditional notions of evidence and effectiveness, thus making them an ideal

group for exploring the reasons for the choice of conventional or CAM treatments in the face of their illness. (Broom and Tovey 2007)

Interviews are appropriate techniques for researchers who seek to understand how people feel about something and allow interviewees to express ideas in their own words (Esterberg 2002).. Thus, people can discuss their experiences naturally, rather than forcing their experiences to fit into pre-conceived categories (as with most quantitative, standardized surveys).

Content analysis is appropriate for this study because this systemized text analysis reveals underlying meanings and ideas through patterns in elements of text and images. (Babbie 1999) The focus on these meanings helps to illuminate the cultural contexts in which texts are produced. Content analysis is especially useful for examining large volumes of data and the analysis of messages in communication (Holsti 1969), such as those we see in treatment center websites. Though the interpretation of the content may be different from what was intended content analysis also allows the accessible and inexpensive opportunity to study social phenomenon without interfering with it. (Krippendorf 2004)

CHAPTER IV

CONTENT ANALYSIS

Commonalities in all sites

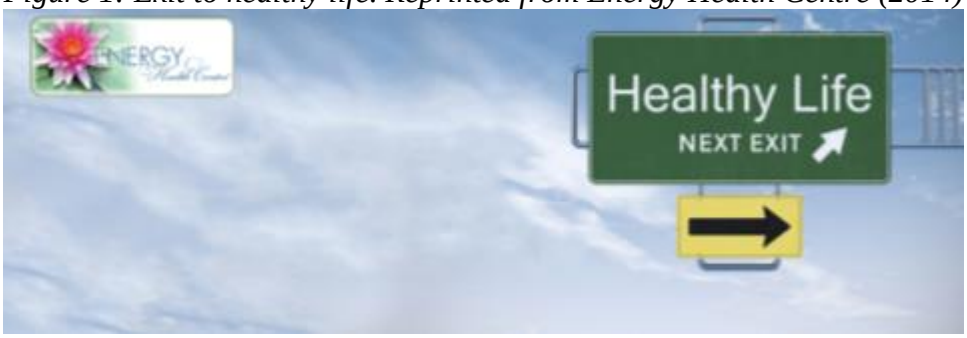
While there are some major differences between the websites for traditional and alternative treatment centers, there are some commonalities across all of them. They all emphasize the importance of patients taking control of their health through preventative measures, becoming well and communicating with their physicians. They also all give patients an idea of what to expect on the first visit, endorse bringing a friend or family member to appointments, discuss payment and insurance, and present images of an idealized friendly neighborhood doctor, while utilizing the analogy of cancer as a battle, a team sport or a journey, which can potential create a "new normal" for patients.

Self efficacy in prevention, treatment and communication

All of these websites emphasize the importance of prevention and maintenance of a healthy lifestyle, consisting of a healthy diet, regular exercise, skin care, minimal risk behaviors (smoking, drinking and unprotected sex), regular doctor visits and vaccinations, and the management of stress. All of these facets of a healthy lifestyle are presented in a way that indicates that the patient is responsible and needs to take control in order to maintain their health and prevent disease, as seen in this direct quote from the website of Integrative Functional Health Center, "Staying informed and taking control of your health can go a long way in preventing disease or successfully managing a condition you may have." (Integrative Functional Health Center 2016) In this way, they emphasize that it is the patient's job to not only take control of their health, but to stay

informed and knowledgeable in order to prevent illness and maintain health. This image from the website of Energy Health Centre of an exit sign for "Healthy Life" (see Figure 1) seems to illustrate this idea that healthy living is a path one chooses and that being healthy is ultimately in the hands of the patient to control.

Figure 1: Exit to healthy life. Reprinted from Energy Health Centre (2014)



Similarly, Texas Oncology offers guidelines for reducing cancer risk, repeatedly stating, "you can take control of your health and reduce your cancer risk by following some simple guidelines," (Texas Oncology 2016) thus emphasizing that not only caring for cancer, but risk reduction is something that is the responsibility of the patient.

Texas Oncology notes that the combination of a high-fat diet and obesity increase the risk for numerous cancers and other health issues, which is echoed by other sites. (Texas Oncology 2016) According to their website, "in 2016, cancer is expected to claim an estimated 595,690 lives in the United States. About 20 percent of those deaths could be prevented through maintaining a healthy weight, limiting alcohol consumption, healthy nutrition, and physical activity. Adopting a healthy lifestyle that includes a well-balanced diet full of nutrients that lower the risk of disease is important

for overall well-being and critical to both preventing and fighting cancer." (Texas Oncology 2016) All sites encourage making healthy decisions at the grocery store as they impact daily meals and, although specifics differ, all cancer specialists would say that a healthy diet is beneficial (MD Anderson Cancer Center 2016). M.D. Anderson, one the best known cancer treatment centers in the country, states that "making the right food choices is a powerful cancer prevention tool" and invites visitors to "find out how to fight cancer with proper nutrition." (MD Anderson Cancer Center 2016) Eating certain types of foods, such as fruits and vegetables, is associated with a lower cancer risk. Since studies have shown that obesity can increase cancer risk, maintaining a healthy weight can also help reduce cancer risk. (Texas Oncology 2016) Additionally, eating a variety of healthy foods can help prevent weight gain and decrease body fat (MD Anderson Cancer Center 2016), so eating the correct diet has the two fold benefit of helping to maintain appropriate body weight and to supply the body with sufficient nutrients.

That being said, all of the sites provide some sort of nutritional service/consultation and most provide guidelines on their websites. These guidelines endorse a diet high in fruits, vegetables, whole grains and legumes—in other words, most foods should come from plant sources. They expand on these guidelines with specific vegetable recommendations—dark leafy greens and cruciferous vegetables—these particular foods score high for containing many anti-cancer substances, such as isothiocyanates." (St Joseph Cancer Center 2016). They also promote the idea of consuming a variety of seasonal fruits and vegetables, including berries. Texas

Oncology and St Joseph's use the cup measurement for recommended servings—at least 2.5 cups of fruits and vegetables per day, while M.D. Anderson utilizes plate guidelines—2/3 of the plate should be vegies, fruits, whole grains, or beans and 1/3 of the plate or less should be animal protein. All websites also advise limiting certain foods and drinks. They advise people to eliminate or reduce their intake of red meat, processed meats, foods that are high in fat and sodium, sugary drinks, processed/refined grains, energy dense foods and alcohol. With respect to alcohol, if consumed at all, they advise no more than one beverage per day for females and no more than 2 beverages per day for males. According to St. Joseph's, "the risk of various types of cancer, including breast, colon, lung, kidney and liver, increases with the amount of alcohol you drink, and with the number of years you've been a drinker." (St. Josephs Cancer Center 2016) Charred food should be avoided because it creates carcinogens and it is also best to avoid sugar, both white and brown, and heavily salted, smoked and pickled foods, which can lead to higher rates of stomach cancer. Avoiding soft drinks, French fries, chips and snack foods that contain trans fats, and food and drink additives such as aspartame is also advised.

These specific guidelines come primarily from traditional sites who, ironically, show very few images of healthy food. The only two are from St. Joseph's (see Figure 2) and MD Anderson (see Figure 3), seen below, depicting salads.

Figure 2: Salad. Reprinted from CHI St. Joseph Health (2016)

Figure 3: Woman with salad. Reprinted from MD Anderson Cancer Center (2016)

The alternative sites who do offer nutritional services, but, on the other hand, do not explicitly state diet guidelines, still represent these ideals through their images of food. The image below from Energy Health Centre depicts food that falls within the healthy recommended guidelines: fruit, vegetables and lean protein (what appears to be fish, so not red meat), with the proportion of vegetables and fruit being much larger than that of the meat. (see Figure 4)

Figure 4: Food proportions. Reprinted from Energy Health Centre (2014)

Health Blossoms features images that only portray fruits and veggies and no meat. In the rolling header, there are images of a very fresh onion, tomato and avocado; a pink smoothie, strawberries, blueberries, mango; and an apple with measuring tape around it, dumbbells in background. This last image (see Figure 5) seems to convey this idea that diet and exercise are important to weight and health.

Figure 5: Apple with weights. Reprinted from Health Blossoms (2016)

Rather than provide self-serve guidelines and offering nutritional services, these centers provide images that fall in line with these guidelines, but present their nutritional services as a component of what their patients receive from them that leads them down the path to better health. At Innovations Wellness Center, "Dr. Wilson teaches patients to use diet, exercise, lifestyle changes with traditional and cutting edge natural options to

enhance their bodies' ability to ward off and combat disease. Dr. Wilson crafts comprehensive wellness plans that blend the best of modern medical science and traditional natural approaches to not only address health concerns and chronic conditions, but also to prevent disease and restore health." In this way, Dr. Wilson is using a combination of traditional and alternative medicine and diet to enhance the body's natural ability to prevent illness and maintain health. Similarly, at the Sebring Clinic, nutritional consultation and metabolic fitness training are part of the treatment process. At Integrative Functional Health Center, extensive nutritional testing is done at the same time as the other lab work in order to determine which nutritional supplements would work best for patients, which begins to get at this idea of taking a general guideline and applying it specifically to each individual. The website notes "personalized medicine, while based upon genomic knowledge of the individual,requires equally essential personalized environmental information as well as the understanding of every subject's capacity for health-promoting behaviour." (Sebring Clinic 2016) In other words, wellness is not just about what people's bodies need for optimum health, but also what people have the capacity to do, on their own, to take control of this aspect of their lives. Energy Health Systems provides "affordable, state-of-the-art nutrition programs individualized to meet the needs of your unique digestive and culinary limitations." (Energy Health Systems 2016) Through positive support and education, this nutritional guidance is said to help fight a number of health conditions and their effects. This personalized instruction is said to be more affective in motivating clients to make lasting changes, which ultimately lead to better health.

Texas Oncology emphasizes that it's not just in prevention that these measures are important, but also during treatment. "One of the most important things you can do while you're in treatment is to take care yourself. Eating a healthy diet and exercising regularly not only help you maintain your physical strength, but also help keep your body strong for the fight." (Texas Oncology 2016) Ensuring proper nutrition during cancer treatment is critical to recovery. However, cancer and its treatments can change how you taste, swallow, or chew your food, and can temporarily change how your body tolerates certain foods and absorbs nutrients. Proper nutrition for a patient undergoing treatment can vary depending on the patient's specific type of cancer, treatment, and the side effects they experience. "A healthy diet is an essential building block for allowing the body to repair itself and resist infection. Thus, what one eats before, during, and after treatment is very important for maintaining strength." (Texas Oncology 2016)

Just as there are dietary recommendations for preventing cancer, there are recommendations for patients undergoing cancer treatment. In order to help the body repair tissue and maintain strength, eating plenty of proteins and calories is advised. Good fats (found in vegetable oils and seafood) help the body protect tissue and carry vitamins through the bloodstream, and nutrient-rich carbohydrates (fruits, vegetables, and whole grains) supply energy and promote organ health. For proper hydration and cell functioning, consuming plenty of water is essential.

The importance of consulting a physician before taking supplements or herbs or trying any particular diet is heavily stressed by both Texas Oncology and MD Anderson. Texas Oncology offers nutritional counseling at some of their centers to help patients

plan a diet that meets their nutritional needs and also satiates them. They also make referrals for said services (which are required in order for patients to utilize these services) and note that it is not usually covered by insurance. MD Anderson has complete nutrition services with licensed dietitians and specialists from their Clinical Nutrition who work with a patient's health care team to identify opportunities for nutritional intervention or support. (MD Anderson 2016)

Nutrition is a critical component in the prevention and successful treatment of cancer. Both alternative and traditional treatment centers emphasize its importance and the idea that this is a way for patients to take control of their health. All sites emphasize that there is a preferred way for patients to practice good nutrition and, although they all offer some sort of guidelines as to what that might be, none of them provide these services to the patient for free. Alternative centers offer nutrition services as a key component of the patient's treatment, as proper nutrition will restore the body to its natural state. Traditional treatment centers offer nutrition services, but note that these are often not covered by insurance and they are not part of the patient's actual treatment plan, even though they may affect the success of treatment.

In spite of the fact that some of these sites boast that they even take into account the environmental factors that can affect a patient's ability to eat healthy and stick to a plan, and therefore, their end success, they still fail to take into account a very critical factor: monetary resources. Healthy food is not necessarily affordable and neither is cancer treatment, particularly if it is not covered by the patient's insurance. If nutritional counseling is an additional fee on top of what is being paid for treatment (as it is with

traditional centers) and is not covered by insurance, then the population that is able to obtain these services is limited to those of higher socioeconomic status. This becomes even more problematic when all sites imply that, to eat in this way, is a part of what it means to take control of one's health through prevention of cancer and improving chances of treatment success. In effect, a "good patient" who, going along with the idea of Parson's sick role, wants to become well, must do whatever is necessary in order to follow these guidelines and/or obtain these services in an effort to exit the sick role and become healthy. Not doing so, regardless of the reasoning behind it (lack of financial resources, in this case) is to not do everything possible to become well, and thus creates a strain on the patient as they are unable to fulfill the role of a "good patient" who is as proactive as possible on their quest to good health. This also effectively diffuses responsibility from the organization back to the patient.

Exercise

As has been established, obesity is a major risk factor for cancer. It has been demonstrated that being overweight increases the risk of postmenopausal breast and colorectal cancers, and experts suggest up to 40 percent of several major cancers may be attributed to obesity and lack of physical activity. Being overweight can increase the risk of cancer by causing a higher production of hormones, including insulin, which may stimulate cancer growth. (MD Anderson Cancer Center 2016, Texas Oncology 2016, St Josephs Cancer Center 2016) "It is estimated that more than half of a million people die from cancer each year, almost 1 in 4 deaths, and up to one- third of these cancer cases are linked to poor nutrition, lack of exercise, and excess weight. Obesity will contribute

to an estimated additional 500,000 U.S. cancer cases by 2030. 100,000 of these cases could be prevented if every adult reduced their BMI by 1 percent.“ Statistics on St. Joseph’s website state that evidence shows that losing just 5 to 10 percent of one’s body weight may result in improved health.

Therefore, establishing habits of healthy eating and physical activity to prevent being overweight or obese can reduce the risk of many cancers. As stated on MD Anderson’s website, “Cancer prevention and good health go hand-in-hand, especially when it comes to physical activity.” According to the National Cancer Institute, more than 50 percent of the U.S. population fails to routinely exercise. (MD Anderson Cancer Center 2016) One in four Americans has no physical activity or leisure time, and two-thirds of adults are considered overweight or obese. The American Cancer Society (which all sites, traditional and alternative, link to with regard to information and fact sheets, including those in diet and physical activity) recommends that average healthy adults participate in a minimum of 75-150 minutes of moderate to vigorous exercise per week for the purpose of maintaining health and reducing the risk of disease, including cancer. The only photos depicting physical activity appear to convey vigorous exercise—one from MD Anderson with a couple running (see Figure 6), who appear to be enjoying themselves and smiling and the other from St. Joseph’s (see Figure 7) of a group of people who are in a plank position, looking very serious, participating in some sort of group class that looks very much like an outdoor bootcamp. These individuals are all relatively young, predominantly white, (though there are some African American individuals in the photos) and they all appear to be quite healthy, physically fit, and

strong. This is in stark contrast to the presumed reader—a patient who has cancer. Cancer patients are generally older and not particularly healthy or physically fit. This presentation of an idealized body type may be intended to evoke a sense of inspiration for these patients. If they come to this hospital and follow these guidelines for preventative care through diet and exercise, they might be able to obtain this level of health and fitness.

Figure 6: Couple running. Reprinted from MD Anderson Cancer Center (2016)

Figure 7: People in plank. Reprinted from CHI St Joseph Health (2016)

Combinations of vigorous and moderate activity are said to be good and it is best to incorporate at least 30 minutes of physical activity in your daily routine —more being

better. The periods of daily exercise may be broken up into 10 minute increments throughout the day, allowing for convenient and varied physical activities. For those already fighting cancer, physical activity has been shown to have numerous health benefits including a lower risk of heart disease and diabetes; healthier bones, muscles, and joints; improved circulation; reduced nausea and fatigue; and more control over weight along with an improved quality of life. One benefit of exercise for cancer patients, in particular, is a reduction in stress. (St Josephs Cancer Center 2016, MD Anderson 2016, Texas Oncology 2016)

Stress

All treatment centers emphasize the idea that minimizing stress is part of staying healthy, in general, but also that it is especially important during cancer because stress can weaken the immune system and make it harder to remain healthy. (MD Anderson Cancer Center 2016) MD Anderson acknowledges that stress is an inherent part of cancer, but encourages patients to identify and utilize coping mechanisms such as breathing methods, meditation or yoga, trying new hobbies, getting more sleep and starting an exercise routine. Some websites, such as Texas Oncology, encourage patients to maintain their physical activity level, stating that moderate exercise several times a week not only improves health but lowers stress levels. (Texas Oncology 2016) Indeed, in a patient testimonial from the Sebring Clinic, a patient discussed how lifestyle change--including physical activity, diet and nutrition--allowed them to be better able to deal with stress and gave them more energy, all of which contributed to their improved health and becoming well.

Texas Oncology discusses stress outside of the context of maintaining an active lifestyle, stating that "managing stress, balancing career and treatment, and maintaining personal relationships are also important aspects of overall wellness." (Texas Oncology 2016) MD Anderson notes that stress can affect treatment decisions and encourages patients to talk to their physicians, saying, "don't be afraid to talk to your doctor or nurse about your feelings and the amount of stress in your life. Let them know if fear is keeping you from making decisions about your treatment or if you are having conflict in your relationships." (MD Anderson Cancer Center 2016) This stress is seen as debilitating to more than just health, but also relationships and treatment decisions. For this reason, it is important for patients to take control of this stress, either through coping mechanisms or by speaking with their physicians.

Communication/Treatment

Speaking with physicians and practitioners is highly encouraged as another way to take control of one's health. MD Anderson's "Speak up Campaign" sponsored by the Joint Commission (MD Anderson Cancer Center 2016) encourages employees and patients to help each other improve health care safety by getting involved in their care and speaking up if they have questions or concerns. Tips for how to do this are offered with the statement, "As a patient, you are an essential member of the health care team, and your health care providers are valuable sources of information for your safety questions. If there's something you don't understand, ask again. It's your body and you have a right to know." Those tips include encouraging the patient to have the doctor mark the area that surgery will be performed on, telling the medical professional if the

patient thinks they are about to receive the wrong medication, and making sure the practitioner is wearing identification and washes their hands before providing treatment.

Similarly, Texas Oncology encourages patients to bring up concerns to their doctor and healthcare team because they are the experts on their bodies. (Texas Oncology 2016) Ultimately, patients are urged to take an active role in their care and make the treatment decisions that are best for themselves and their loves ones (Texas Oncology 2016). They are also urged to make decisions on their terms about when to talk to family and friends about their illness. (Texas Oncology 2016) In all of these decisions as well as the materials for the individual sites, communication is emphasized as a very important component of minimizing stress and maintaining health. It is the patient's responsibility to communicate with family and physicians and to take an active role in their treatment and the decision making process, just as much as they would with lifestyle changes for the purposes of treating or preventing illness.

These ideas add yet another item to the list of things that make a good patient: communication. Communicating is not only an aspect of minimizing stress, but also part of receiving optimal care. Again, as a sick person, patients should want to exit the sick role and resume their normal role in society. Diet, exercise and stress reduction will all aid the patient in avoiding illness and becoming well, faster. Communicating with friends and family will assist in reducing the stress, so this is part of the previously mentioned measures that patients can take to help them become well more quickly. However, while taking control of one's health might involve being more proactive with treatment decisions and questions for physicians, the implication of some of these

guidelines is that things that are ultimately the responsibility of the health care professional are now the responsibility of the patient.

For example, in MD Anderson's speak up campaign, they encourage patients to take control of their care by saying something if they see that a medical professional has not washed their hands or they see a difference in the medications they are receiving. Even though medical professionals are expected to maintain high standards of sanitization and should be very thorough with their medication administration, the responsibility is placed back on the patient to make sure that the doctor or nurse does things correctly.

This is problematic for several reasons, the biggest one being that patients are now not only responsible for taking care of themselves independently of the physicians, but also for making sure that the physician is doing their job, correctly. With the known instances of malpractice and staph infections in hospitals due to negligence, this adds an element of stress to the patient's life at a time when they should be placing this aspect of their care in the hands of a professional. It also creates an environment of mistrust and negatively impacts the relationship between doctor and patient if the patient is continuously questioning whether or not they have done their job correctly. However, because it has been implied many times over that patients should take control of their health by engaging in this sort of dialogue, this has the potential to again create role strain and role conflict (between the role of patient as subordinate to the doctor and the sick role as a person who is proactive in their quest to get well by questioning the doctor when it seems called for) for the person who is ill, thus adding more stress for the person

who needs to reduce it to help themselves become well. Patient responsibility in communicating and asking questions is stressed across all sites—traditional and alternative—as an important component of the process of getting well, along with adhering to healthy diet and exercise guidelines.

Doctor visits, skin care and risk taking behaviors

Besides taking the necessary diet and exercise measures, there are other components to prevention of cancer that people can actively take part in that these treatment centers promote on their websites. Among those are visiting doctors and getting regularly screened and vaccinated, taking care of one's skin and minimizing risk taking behaviors such as unsafe sex and smoking.

According to St. Joseph's, "Cancer doctors and cancer specialists universally agree that making good lifestyle choices is the best form of cancer prevention. Despite conflicting reports about what does and does not cause cancer, the Cancer Prevention Foundation offers foundational steps for preventing cancer." (St Josephs Cancer Center 2016) Among those are seeking regular medical treatment and routine screenings.

Texas Oncology highlights the importance of screening, stating, "Screenings are the most effective tool available for identifying cancers in their earliest stages –often before you experience any symptoms." (Texas Oncology 2016) This sentiment is echoed in the following photo (see Figure 8) from Christus Spohn's free screening program for lung cancer.

Figure 8: Lung cancer screening. Reprinted from Christus Spohn Health System (2016)

Some centers, like Innovations Wellness Center offer services like self-directed labs to literally put those types of screenings into the patient's hands, stating, "We help put your health in your hands. Early detection and prevention are vitally important to your health." (Innovations Wellness Center 2016) Other treatment facilities offer the same screening opportunities but, again, as with diet and exercise, provide guidelines that people can utilize to then take the necessary steps to take control of their health. Websites for centers like Texas Oncology, MD Anderson and St Joseph's provide checklists of which screenings that should be done based on age, emphasizing the ability of screening and self exams to diagnose cancer at its earliest stages, when treatment will be most effective and potential for minimally invasive treatment and survival will be optimal. (St Josephs Cancer Center 2016, Texas Oncology 2016, MD Anderson Cancer Center 2016)

Many of the screenings are self-exams that can be performed at home, such as breast or testicular exams. Texas Oncology sites the following statistics, seemingly as motivation to men to take control of their health by heeding their advice:

"Testicular Cancer, commonly diagnosed in men ages 20 to 39, has been increasing for several decades. If treated early, testicular cancer patients have a 99 percent survival rate after five years."

Though exams are not as easily performed, similar statistics are cited regarding the importance of checking one's colon health:

"Colon cancer is the second-leading cancer killer of men and women combined, and is among the most difficult to detect because it lacks symptoms in early stages. Starting at age 50, you should discuss the most appropriate screening test with your physician. If you have a higher risk, based on your family history, your doctor may recommend starting screening earlier."

In this instance, even though exams cannot be performed by the patients themselves, the threat of this type of cancer is made more concrete by the offering of statistics and lack of detectability. (Texas Oncology 2016) Again, the idea seems to be that making the possibility of the disease more concrete will motivate people to take the necessary measures to maintain their health. In this type of screening, patients would have to visit their doctor, which is yet another way that patients are encouraged to take control of their health and prevent illness.

As part of maintaining good health and preventing illness, all sites encourage patients to see their doctor, regularly. Texas Oncology, however, devotes a little time to the idea that men and women practice different lifestyle habits, including propensity to go to the doctor. Because men are statistically more likely to engage in risky behaviors like smoking and drinking alcohol and also tend to carry excess weight, they are at higher risk for cancer (because all of these things are correlated with cancer). Therefore, it is seen as critically important that men take control of their health by not only making the suggested lifestyle changes, but also by seeing a doctor regularly for physical exams,

citing that “one in four men doesn’t see a doctor at least once a year.” (Texas Oncology 2016)

While most of the health concerns and cancer risks are the same for women as they are for men (aside from breast cancer screening and regular PAPS), the approach to conveying women’s need to see their physician regularly is very different from the one taken with men. Rather than a focus on risk taking behaviors or lack of desire to take care of themselves, traditional websites focus on the idea that women are so busy caring for others, that they neglect to do the same for themselves with statements like, “Most likely, you’re the chief healthcare officer for your family. However, it’s equally important to take care of yourself.” (Texas Oncology 2016) At first glance these approaches might appear to be sexist or based on inaccurate gender stereotypes. However, sociological research supports the notion that men do, in fact, avoid seeing physicians and engage in more high risk behaviors, while women tend to be the healthcare gatekeepers/care takers of the family, spurring on other members to practice healthy habits and visit a physician when needed.

According to the sites of Texas Oncology, Christus Spohn, MD Anderson, and St Joseph’s, one of those high risk behaviors—smoking— is the most important thing a person can avoid in order to prevent cancer. Lung cancer is responsible for the most cancer-related deaths in Texas and has one of the lowest survival rates. Only 17 percent of lung cancer patients live more than five years beyond their initial diagnosis and smoking causes nearly 90% of all lung cancers. (MD Anderson Cancer Center 2016) Smoking and tobacco use are associated with 15 different kinds of cancer, including

lung, bladder, cervix and kidney (St Josephs Cancer Center 2016); increases the risk of heart and chronic lung disease (Texas Oncology 2016); and is accountable for at least 30 percent of all cancer deaths. (Texas Oncology 2016, MD Anderson Cancer Center 2016) There is no safe tobacco product and even living with a smoker can be hazardous to a person's health. People who live with smokers are more likely to develop lung cancer and even limited exposure to secondhand smoke can raise your heart disease risk. (MD Anderson Cancer Center 2016, St Josephs Cancer Center 2016)

All sites acknowledge that there are national programs available for advice and support for those who want to quit smoking. Texas Oncology offers a smoking cessation fact sheet with tips on how to successfully quit and both MD Anderson and St. Joseph's state that doctors and cancer specialists can refer patients to products and strategies to help people quit.

The only related image to cessation of smoking is underneath the sentence, "Not using tobacco is one of the best actions you can take for cancer prevention and your overall health," on the MD Anderson website under the portion of the site dedicated to cancer prevention. It features a person wadding up a pack of cigarettes as though they are garbage and are going to be disposed of (see Figure 9). This image aligns with what health care professionals would like people to do as a critical step in taking control of their health and reducing their cancer risk: eliminating tobacco products.

Figure 9: Trashing cigarettes. Reprinted from MD Anderson Cancer Center (2016)

Practicing safe sex and vaccinating against certain viral infections, particularly if an individual is sexually active outside of a mutually monogamous relationship, are important for health Two that should be vaccinated against are Hepatitis B and Human papillomavirus (HPV). Hepatitis B is blood born disease that can be transmitted without sexual contact as well and increases the risk of developing liver cancer. HPV is a sexually transmitted virus that can lead to cervical and other genital cancers along with squamous cell cancers of the head and neck and is not exclusive to women. St. Joseph's cites a recent study that one in two sexually active men has HPV and notes that it can also lead to anal and penile cancer and encourages anyone 26 or younger to get the vaccine. MD Anderson also informs patients that getting an HPV vaccination for children can reduce their cancer risk and, below this information, displays the following image of a smiling woman—presumably, a mother and her 2 daughters (see Figure 10),

who she has recently vaccinated in order to improve their chances of staying cancer free by immunizing them against HPV.

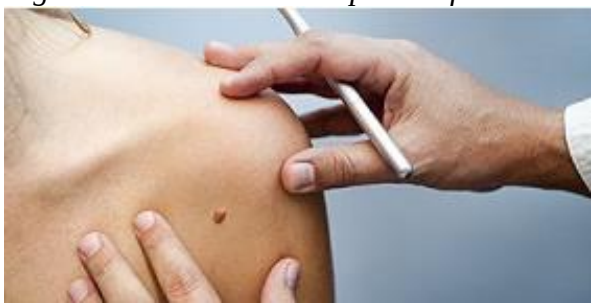
Figure 10: HPV screening. Reprinted from MD Anderson Cancer Center (2016)

The final risk taking behavior that these sites encourage people to avoid is long exposure of skin to the sun. Skin cancer is common, yet highly preventable by following some guidelines. Limiting exposure to the sun goes a long way in preventing skin cancer and melanoma. To that end, they recommend wearing sunscreen at all times, not just during the summer, and being generous with sunscreen by applying it heavily and regularly as long as you are outside. They also advise against being in the sun between 10am and 4pm as midday sun has the strongest rays and avoiding tanning beds and sunlamps as they are just as damaging as natural sunlight. St. Joseph's also endorses staying in the shade as much as possible when outside and covering up, as well.

MD Anderson also endorses self-examination of the skin, recommending that individuals check their skin once a month for any changes in moles or other marks that

could be signs of skin cancer. If patients notice any changes to their skin, they are instructed to tell their doctor right away. Beneath this suggestion, the following picture (see Figure 11) of what appears to be a woman having a mole examined by her physician can be found.

Figure 11: Mole exam. Reprinted from MD Anderson Cancer Center (2016)



Screening suggestions are again presented in a way that places the responsibility on the patient. Though patients do not yet know they are sick when they obtain their screenings, there is an emphasis on taking measures to avoid the sick role, entirely. Avoiding the sick role through minimizing risky behaviors such as unsafe sex, smoking cigarettes and practicing sun safety, along with getting vaccinations and screenings, is part of the duty of individuals, much like taking all steps to improve health is the duty of someone who has taken on the sick role by virtue of illness. In an effort to encourage avoiding the sick role, scare tactics of sorts are used. An emphasis is placed on the need to be fearful of the unknown and the negative consequences that not taking these measures can lead to. These tactics are even geared toward the sexes differentially. For men, the emphasis is on the importance of recognizing that men must take care of

themselves by reducing risk taking behaviors and seeing their doctor because they are not invincible. For women, the emphasis is on the importance of recognizing their own needs, rather than prioritizing the needs and health of everyone else over their own. In this way, these treatment centers are emphasizing the responsibility of the patient in not only sick role exit, but sick role avoidance. They are also emphasizing the importance of themselves in this task by making regular doctor visits and screenings a critical component of avoiding the sick role. They are important because, if a patient wishes to remain well—which is a part of their duty in maintaining their role as a healthy individual—the person must visit the center, see their doctor and utilize these services.

These guidelines and recommendations for living a lifestyle that prevents cancer are presented in a way that inform the reader and also act as a warning or cautionary tale for what could happen if those guidelines are not adhered to. By presenting guidelines and suggestions in this way, patients are encouraged to take control of their own health and be active in the care process as well as the prevention of cancer and diseases that could potentially lead to cancer. The images that accompany these guidelines portray happy, healthy, young and strong individuals, which is not necessarily an accurate representation of the people who are likely to be utilizing the websites. These images of people who are young, fit and healthy imply that following these guidelines will also lead patients to look like these individuals, in spite of the fact that they are very ill and may not have resembled these images prior to being diagnosed with cancer, which is yet another enticement to utilizing services at the particular facility whose website they are visiting.

Bring an advocate

Though these websites supply plenty of information and guidelines for patients to read, ingest and follow on their own accord, they all acknowledge that, even coming into an appointment informed, the amount of information can be overwhelming. Advice from former patients, care takers and various staff members at Texas Oncology includes that patients need to be prepared to absorb a large amount of information in a small amount of time. For this reason, they suggest bringing a spouse or other significant person (friend or family member) as an "extra set of ears" (Texas Oncology 2016) along to appointments. As stated by Integrative Functional Health Center, at appointments, they "offer much information and the more ears, the better" because, as Texas Oncology puts it, "they may hear something you missed, think of different questions to ask, or even just take notes." (Texas Oncology 2016) There is also a suggestion to bring a journal or a notebook to facilitate taking notes and being sure to utilize the materials and fact sheets that the centers have posted on their websites.

MD Anderson also advises these practices, but, rather than listing these ideas as things for patients to implement, they are listed under the section of the website entitled "Caregiver Duties," subheading, "communicating with the cancer team" (MD Anderson Cancer Center) In order to make communication with the patient's cancer team as effective as possible, they advise caregivers to keep thorough notes of every appointment and to ask questions. Again, they acknowledge that the amount of information and the disease itself are overwhelming and say that keeping detailed notes from appointments can help eliminate miscommunication and help remember items that were discussed and

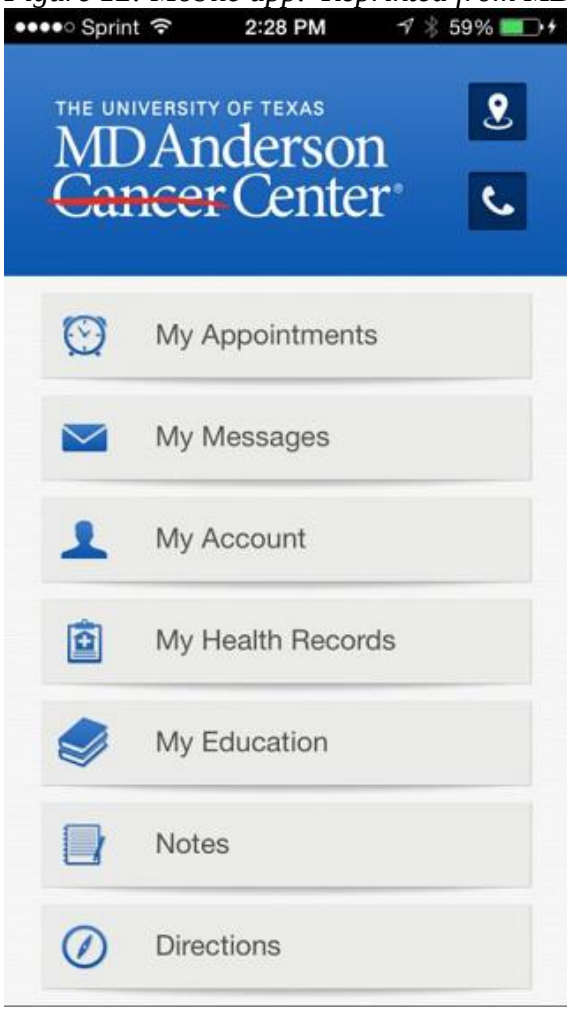
questions that need to be asked. This is interesting considering the previously mentioned "Speak Up Campaign" they have, which encourages patients to speak up themselves if they have questions, etc. It is highly possible that these guidelines are intended to apply to those situations where the patient is not fully capable of advocating for themselves. However, one would think that there would be advice elsewhere for the patient as well that encouraged them to designate someone to do these things, rather than just presuming they would be the responsibility of a third party. These ideas were prevalent in staff and physician interviews and we will return to this subject when discussing those.

Regardless of whether it is the patient's duty themselves or the duty of a family member of the patient, these sites encourage patient's to have a third party present to take notes and ask questions during consults with physicians because the amount of information they are given is so extensive. Rather than being the responsibility of the physician to make sure that the patient fully understands and is able to ask questions with a swift response at any time, it is the responsibility of the patient, in their role as cancer patient, to make sure that they have provided themselves with this type of opportunity to better understand the information they are being given. To understand the information is to have an advantage in the fight against cancer, so all steps are expected to be taken in an effort to obtain that advantage. In spite of the fact that patients may not have the resources of another trusted person that can help them in this manner, all patients are expected to do this in order to take control of their health and, once again, do everything possible to exit the sick role.

Social media

Perhaps not terribly surprising in this digital era with the popularity of social media, all of the sites featured links to their social media accounts. All of the sites had Facebook and Twitter accounts and most had Instagram, YouTube and some sort of online blog, whether that was Tumbler or another site. Many sites had links to online forums and support groups to accommodate those who might live in a remote area or be unable to find transportation to the regularly scheduled meetings that such groups have. Those centers that sold supplements had options to order those online and all of the sites have online patient portals that allow patients to view upcoming appointments, billing statements and balances and submit emails and requests to their physicians. MD Anderson even has a mobile app (see Figure 12) so that patients can keep track of all of the information in their patient portal without even needing to be on a computer or go through the trouble of logging in through a browser on their phone. Instead, people can simply download an app and have all of this information at their fingertips.

Figure 12: Mobile app. Reprinted from MD Anderson Cancer Center (2016)



These sites do everything possible to make many of the resources as accessible as possible to patients. This includes utilizing social media and phone technology. By making themselves present in social media, they encourage more participation and utilization by patients who might otherwise not visit the treatment center website. By offering a phone app, they also appeal to those patients who are less inclined to make the effort to look up the website via internet browser on their phone or maybe only have

access to a phone, but not a computer. The inclusion of links to online support groups is also very useful for patients who don't live near such groups or have reliable transportation to them. If effect, these inclusions make preventative and care measures more accessible for people leaving them with fewer legitimate reasons to not avoid the sick role or efforts to exit it. They also allow these centers to market themselves to those portions of the population that would find these services, or simply this connection to technology, appealing, such as younger generations or those with higher socioeconomic status who might have access to these resources or spend more time connected to technology.

Images of medicine and the "friendly neighborhood doctor"

All of the websites of these treatment centers also feature images that are icons of medicine or portray a very friendly physician who has a close relationship with their patients.

Under their Wellness Center Services section, a section that features many alternative medicine services, such as naturopathic and homeopathic medicine, along with acupuncture, Health Blossom's features the following image of a transparent version of the anatomical man (see Figure 13), showing his skeleton beneath, which is modern take on a familiar image. Historically, this image has also been seen as a representation of a perfectly healthy human and affiliated with the artist, Leonardo da Vinci's, efforts to find a connection between the structure of the human body and the structure of nature. Presently, this image is frequently seen on the front of Anatomy textbooks and is often affiliated with medicine.

Figure 13: Anatomical man. Reprinted from Health Blossoms (2016)

Another common image affiliated with medicine is the stethoscope. The stethoscope can also be found on the Health Blossoms' website, as one of the rolling header images on the home page (see Figure 14).

Figure 14: Stethoscope. Reprinted from Health Blossoms (2016)

A similar image of a stethoscope on top of a prescription pad can be found on the Innovations Wellness website. The stethoscope is a symbol of medicine, as is a prescription pad—a stethoscope is a tool specifically used by medical professionals, much like a prescription pad and, without the authority, a person may not write a prescription. In this way, these two items are not just symbols of medicine, but also symbols of authority. When used on alternative treatment center sites, it is possible that the intention is to ensure that there is a connection between what is stereotypically associated with medicine (allopathic) and a type of medicine that people are not as familiar with (alternative) and may, as a result, think of as being completely unlike the type of medicine practiced by traditional physicians. A stethoscope and prescription pad, in this way, give some legitimacy to this type of medicine in the face of uncertainty and tie it to more familiar images of medicine.

Often, the images of physicians on traditional and alternative treatment center websites, alike include stethoscopes as seen in this photo from Texas Oncology of a woman in blue scrubs, wearing a stethoscope (see Figure 15).

Figure 15: Scrubs and stethoscope. Reprinted from Texas Oncology (2016)

In the following photo from MD Anderson (see Figure 16), we see the only image of a stethoscope in use by a female physician on an elderly patient.

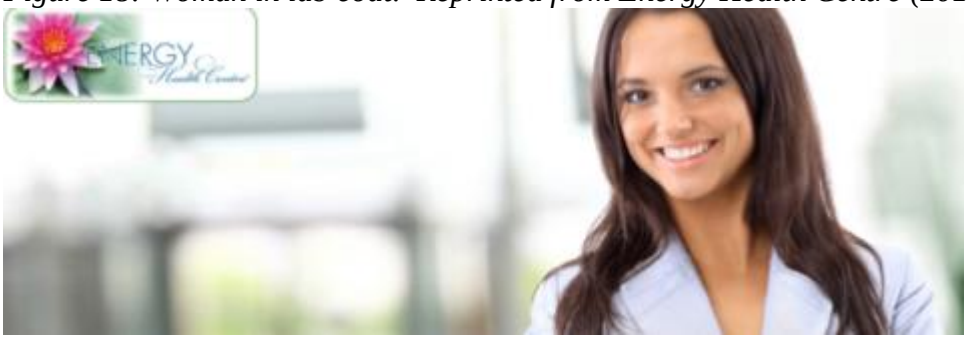
Figure 16: Stethoscope in action. Reprinted from MD Anderson Cancer Center (2016)

More often than not, the stethoscopes are simply worn around the neck of the physician, as seen in this photo (see Figure 17) of the practitioner at Innovations Wellness Center.

Figure 17: Wearing stethoscope. Reprinted from Innovations Wellness Center (2016)

Like the other physician, this physician is smiling and appears very warm, welcoming and friendly. She is also wearing a white lab coat, an article of clothing that is repeatedly worn by individuals on all of these websites. Sometimes, those individuals aren't even physicians. The following image (see Figure 18) of a smiling woman wearing a white lab coat is a header for Energy Health Centre's website. However, there are photos of all of their physicians on their webpage and this individual is not one of them. Interestingly, in the physician photos, none of them are wearing white lab coats, scrubs or stethoscopes, but rather are wearing blouses.

Figure 18: Woman in lab coat. Reprinted from Energy Health Centre (2014)



Similarly, under their "about us" portion of the website, Christus Spohn features the following image of smiling individuals, some of whom appear to be wearing white lab coats and maybe even a surgical mask, for one of them (see Figure 19). They may be staff members, but they are certainly not physicians as those people are introduced on the same page and none of them are these individuals.

Figure 19: Smiling staff. Reprinted from Christus Spohn Health System (2016)

However, they do appear in another photo (see Figure 20), all smiling and wearing the white lab coats, dressed professionally underneath the coats, with the men wearing suit and ties.

Figure 20: Real staff. Reprinted from Christus Spohn Health System (2016)

Even though there appears to be more racial diversity among the physicians at this particular hospital, the stock photo is far more racially diverse. The stock photo appears to show individuals who each represent a different ethnicity, while the actual doctors appear to be of only two ethnic origins: white and Indian American. Similarly, though it is difficult to know for certain the ethnicity of the woman in the stock photo for Energy Health Systems, she does at least appear to be representing a different ethnic group than the 3 female white practitioners on staff. This more diverse representation of the individuals working at these treatment centers than the actual individuals working at these sites, themselves may be intended to appeal to a more racially diverse clientele.

Similar images of people who are presumed to be physicians appear on other treatment center websites, but the individual is generally interacting with a patient.

Because of the size of facilities like Texas Oncology and MD Anderson, only executive directors have biographies and photos on the website, so it is difficult to know whether or not these people are definitely physicians, but based on the fact that these shots appear candid, one is lead to believe that they are. In these photos, the physician is the focal point, so rarely is there a picture of more of the patient than the back of their head. In the following photos from Texas Oncology (see Figure 21) and MD Anderson (see Figure 22), we see two male physicians wearing white labcoats with collared shirts and ties underneath them, smiling as they interact with their patient.

Figure 21: Male doctor 1. Reprinted from Texas Oncology (2016)

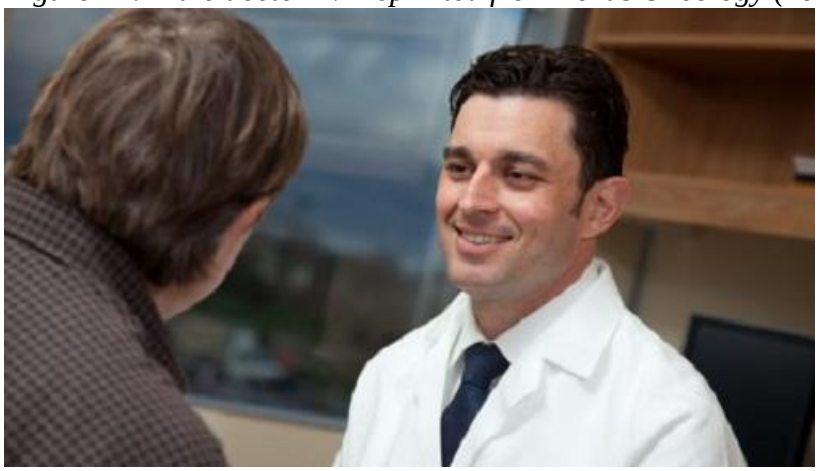


Figure 22: Male doctor 2. Reprinted from MD Anderson Cancer Center (2016)

Again, while we cannot be sure of the ethnicity of either doctor, the two are very different—one darker haired and young and the other lighter haired and older. As previously stated, this diversity may be intentional in an effort to appeal to a wider audience, both in ethnicity and age.

At times, the physician is seen touching the patient as in this image from the website of Texas Oncology depicting a physician—again, smiling in a white lab coat with a collared shirt and tie on beneath—touching the shoulder of a female patient (see Figure 23).

Figure 23: Male doctor touching female patient. Reprinted from Texas Oncology (2016)

Another image like this comes from MD Anderson's website, where we see a smiling female physician in a white lab coat holding the hand of her female patient (see Figure 24).

Figure 24: Female doctor holding patient's hand. Reprinted from MD Anderson Cancer Center (2016)

This same image can be found on the website for St Joseph's. In one image (see Figure 25), we see a smiling female doctor, in her white labcoat, with her hand on the patient's forearm as she is sitting next to him. In the other image (see Figure 26), we see the smiling patient navigator, who, although she is not wearing a labcoat, she is wearing white cardigan over her professional clothing. Interestingly, the female physician and female patient navigators are the only ones who can be seen in any sort of candid photo, much less this sort of image.

Figure 25: Female doctor touching patient. Reprinted from CHI St Joseph Health (2016)

Figure 26: Patient navigator and patient. Reprinted from CHI St. Joseph Health (2016)

These images of physicians touching their patient's shoulder's or arms or holding their hands create a sense that the physician is caring and sensitive to the patient's needs and feelings. There is this idea that there is a certain closeness between the patient and physician, as though they truly care for them and are invested in their best interests. Elsewhere on the site, the phrase "Always here. Always caring." (St Josephs Cancer Center 2016) can be found. These images and phrases create this idea that this kind of treatment is something you can expect. Indeed, in the following photo from St. Josephs, the focus is shifted to the patient and the physician is actually hugging the patient (see Figure 27). The photo bears a caption that reads, "Experience a culture that embraces excellence." This implies that this standard of care is above average and that is what the facility strives for.

Figure 27: Embracing. Reprinted from CHI St Joseph Health (2016)

Beyond the contact and implied care between the patient and medical professionals in these images, there is also, once again, the issue of the depiction of race and ethnicity and even gender in these stock photos, as well as photos of the actual professionals at these sites. In these photos, the majority of the physicians and medical professionals are white and the patients are typically nonwhite. The focal point is always the physician, with the exception of the very last photo, where the focal point is the elderly white patient, rather than the nonwhite nurse who is caring for her. However, the race, age, and gender of the patient are diverse from photo to photo. Much like the stock photos of physicians were more diverse than the physicians were, in reality, in an effort to attract a more diverse group of clients, these photos appeal now to the idea that the clients who receive treatment at these facilities are of a diverse ethnic backgrounds, regardless of whether they reflect the majority of patients who actually receive treatment at these facilities or not. The photos of the white male doctors do accurately reflect the demographic of most hospitals, but they also perpetuate the idea that the majority ethnic group is also the dominant group within the hospital and the minority ethnic group is the subordinate group, just as they are outside of it. The fact that only one of the male doctors is touching a patient, while all of the rest of the images that seem to portray caring through contact are of female doctors also implies that this sort of emotion work is the job of female medical professionals, more so than males. So, again, we see these images perpetuating stereotypes and patterns that are reflected in the larger social context outside of the treatment center. These patients also all seem to be very happy, no matter what sort of discomfort cancer and the treatment process may cause. The

implication is that treatment is not that bad and doctors are provide such comfort that patients hardly notice the unpleasantness of their illness.

This idea of a physician who cares and can be counted on is generally very appealing and targets the primary complaints of most people who are unhappy with the medical system. In this way, the websites counter the stereotype by emphasizing how they provide "old fashioned doctor patient care." All sites recognize that they need to appear authoritative and knowledgeable, yet also friendly and caring if they wish to attract patients. These sites depict either their physicians or their patients as more racially diverse than they actually are, presumably to draw a larger group of people to use their facility.

Payment and insurance

All sites also discuss payment and insurance. Most of the alternative sites let patients know up front that they do not accept insurance of any type. The Sebring Clinic makes a statement regarding the fact that they do not take insurance and Energy Health Systems has a waiver on the appointment scheduling page that requires patients to acknowledge that insurance is not accepted and, as such, all payment will be due in the form of cash, check or credit at the time of service. Integrative Functional Health Center also informs people that, because they do not participate with any insurance providers, they do not accept Medicare payments, will not file any Medicare claims or provide patients with diagnostic codes for patients to file on their own with insurance carriers. (Integrative Functional Health Center 2016) The Burzynski Clinic, however, asks people to bring their insurance ID and prescription ID Cards, stating, "As a courtesy to

our patients, we will submit charges to your insurance and prescription companies. Please notify your insurance company prior to your visit, and you may want to confirm with them if you will need a referral letter. Since we are classified as "out of network" we are unable to accept Medicare, Medicaid and any HMO insurance. If you utilize an insurance broker, we will need that contact information as well." (Burzynski Clinic 2016) So, even though they don't accept the standard insurance, they are willing to file for other types and attempt to help their patients obtain coverage.

In contrast, traditional treatment centers do accept insurance. They are participating providers for Medicare, Medicaid and most commercial insurance plans. Sites like Texas Oncology provide a list and way to verify that their clinics participate with people's insurance carriers and both Texas Oncology and MD Anderson also have a financial counselor onsite to assist patients with claims and any payment concerns. Payment plans are worked out and assistance options for those who qualify are available.

What to expect on first visit

All treatment centers emphasize a desire for patients to have a smooth and comfortable first visit. To that end they dedicate portions of their websites to preparing their patients for what to expect on the first time to the treatment center. To effectively treat a patient, a complete medical history is necessary, so all centers request one, along with a thorough list of current medications including all prescription medications, over-the-counter medications, alternative medications, vitamins, herbs and supplements.

If a patient has already been diagnosed with cancer, the site suggests that any radiology tests or pathology reports should also be included and brought to the first

exam, whether in hard copy or digital form. If there was a referring physician (they are often needed for traditional centers and for one alternative center, Burzynski), a referral letter and/or contact information for the referring physician should also be brought along. In addition to the paperwork and records that patients must bring with them, there is also a packet that needs to be completed prior to the first visit. Most centers note that this paperwork will take about 30 minutes to complete and offer the option of either completing it prior to arrival or arriving earlier in order to complete it when the first get to the facility.

Patients are asked to arrive on time and required to cancel with a minimum of 24 hour notice, otherwise they can expect to be charged for the visit. Depending on the procedures that will be done, there are other requirements for the appointment. Those requirements are specified on each center's site and people are asked to come prepared for those as well.

The sites encourage patients to write down questions before their appointment, and bring those with them, along with a notebook to take notes and possibly, a family member or significant other because the amount of information they receive can sometimes be overwhelming and a second set of ears is helpful.

When patients are diagnosed with cancer, the diagnosis itself is very overwhelming. Because of this, treatment centers provide very detailed guidelines about what to expect on the first visit, so that patients are aware of everything that is going to happen and be expected of them, well before they arrive. Because there is so much information to disseminate on this first visit, all centers advise that patients bring

questions, note taking implements and, if possible, another person to catch anything they might miss. In this way, these centers are trying to do everything possible to make patients comfortable and lift some of the burden of the unknown off of them at a time when so much is already quite uncertain. Cancer is not only a very physically and emotionally draining disease, but also a large financial burden. While health care may be a service intended to help people, it is still a for profit business that requires money to continue. To that end, payment arrangements must be discussed. Though centers may attempt to get insurance to cover these services and provide financial counseling services, they still exercise a hard line when it comes to patient payment. Because treatment is necessary for survival, payment itself may become a whole new stress for patients, but again, these centers provide information to prepare patients for what to expect about payment before they ever arrive.

Cancer analogies

As in the literature, throughout the treatment center websites, analogies comparing cancer to a fight or battle were recurring. Along with this comparison of Cancer to a battle one must fight, there were two additional analogies: cancer as a sort of athletic endeavor that required a team effort and cancer as a journey. Additionally, there was another idea, "the new normal," came up repeatedly.

Cancer analogy: team

Treatment Centers often discuss their approach to treating cancer as a team effort. According to Texas Oncology, "treating cancer takes a skilled team." (Texas Oncolgy 2016) MD Anderson also cites this approach as a trademark of their center,

saying, “Most new patients who come to MD Anderson every year are treated in one of our specialized cancer care centers or clinics, which embody the team approach to cancer care that has become an MD Anderson trademark.” (MD Anderson Cancer Center 2016) However, Christus Spohn also utilizes a “multidisciplinary team approach that means they work together to create a treatment plan that’s tailored” to their patient’s needs (Christus Spohn 2016) and St. Joseph’s “offers a comprehensive program that is committed to a multidisciplinary team approach to cancer treatment.” (St Josephs Cancer Center 2016) They elaborate the various duties of the cancer team and the various titles/roles of the members of the team, saying that their commitment to a “multidisciplinary team approach”(St Josephs Cancer Center 2016) allows them to approach cancer with passion and that passion is used to help the patient. At St. Josephs, patients will have access to the support and services they need, “plus an entire team of compassionate cancer specialists alongside them (you) every step of the way.” (St Josephs Cancer Center) Texas Oncology also elaborates on the roles of members of the team stating “Your medical oncologist is the quarterback of your cancer treatment team” (Texas Oncology 2016) further utilizing this analogy of cancer as a game or athletic endeavor that someone must be in charge of and that a team effort is required if one wishes to have success and “win.”

In fact, there is an entire section of the website for Texas Oncology entitled, “My Oncology Team” (Texas Oncology 2016) Outside of the specific duties of the team, they call attention to the fact that the patient themselves is a very important part of this team and integral to its success. “Some of the most important people you will meet are on

your care team. They provide compassionate care and are ready to fight by your side. Your team members may Include: (list of positions). You play a vital role on this team." (Texas Oncology 2016) They go on to say that the patient knows their body best, so it is critical that they speak up about how they are feeling and, as mentioned previously, emphasize that the patient is in control of their health and treatment process just as much as they are in control of prevention. In this way, they are emphasizing the patient role in this team effort toward good health and the idea that the team cannot be successful without the patient's participation.

Interestingly, Texas Oncology also has a retail store called the "I Can" store. A percentage of purchases go to the Texas Oncology Foundation to advance cancer research and treatment and, according to Texas Oncology, buying a shirt or hat with the logo and slogan on them is "a great way to show your fighting spirit, as well as help others in their fight." (Texas Oncology 2016) This idea is very reminiscent of wearing the shirt of the team or school that you support to a sporting event. Wearing your team/school shirt shows your support of the team and shows that you have a similar mentality, which is what this site says these items do, too, only that spirit and solidarity is as part of a team fighting cancer.

Patients and physicians are not the only ones who are part of this team. According to Texas Oncology, "Every patient is surrounded by caregivers that stand with them in their cancer fight. Helping a friend or loved one navigate their cancer treatment is a vital role that can take many forms. You're an essential part of the treatment team." Similarly, MDA Anderson notes that "communicating with the health

care team" (351) is a critical role that the caregiver plays and, again, success is not possible without this member of the "team."

Cancer analogy: battle

All sites use an analogy that compares going through cancer to fighting a battle. Cancer patients are often seen as responsible for "fighting" their cancer and in a "battle" to eradicate it. MD Anderson illustrates this idea well with the following quote:

> "Fighting cancer might be the toughest thing you ever have to do. It's a 24-hour-a-day job that can drain both your brain and your body. Cancer can hit you on multiple fronts — the disease itself, the aggressive treatments used to fight it and the side eects of those treatments. Dealing with this barrage of physical eects takes its toll on you emotionally as well."

(MD Anderson Cancer Center 2016) Several battle terms are used—besides fight, they mention being hit on multiple fronts and all in the context of a tough fight that will be draining and exhausting and necessary.

If it is the patient's job to fight cancer, the hospital/treatment center and doctors have the job of assisting the patient in that endeavor. Put simply, in more military terminology, as the Burzynski clinic does, their "mission is to beat cancer."

According to Burzynski, "It is not just about the concierge care we provide when they come in the door scared about their evaluation and treatment. It is about helping them fight every day, helping them fight to win the battle." In other words, while providing care and reassurance may be part of what the center does to help patients, it is not all. They do more than that to help them, on a daily basis, take up arms against cancer.

Texas Oncology cites the way that they pursue more effective treatments and their community approach as ways that they go above and beyond to help their patients in their battles. The community approach of Texas Oncology is to provide care close to home, so that patients have the support of loved ones along with their physicians. "Our patients deserve access to the best cancer care available, the confidence to fight cancer, and the critical support of family and friends nearby." (Texas Oncology 2016) This closeness to home and abundance of support provides patients with more "confidence to fight" because they are in more familiar territory and that support gives them strength. Finally, Texas Oncology also emphasizes the value of the individual patient and their unique circumstances. In the following statement, they reiterate the importance of each patient and their part in helping patients achieve a victory over cancer: "Every patient who entrusts their care to us is unique, and every fight, critical. We provide high-quality, high-touch evidence-based care to help you achieve "More breakthroughs. More victories." in your fight against cancer." (308)

As a patient goes into "battle" it is important for them to be ready. In their "what to expect" section, Texas Oncology begins with the phrase "Preparing to fight cancer naturally raises many questions," (Texas Oncology 2016) as they begin to list frequently asked questions and what to expect as they begin their treatment. One of those topics is "Nutrition for Patients Fighting Cancer." (Texas Oncology 2016) Similarly, MD Anderson calls their recommended diet the "Cancer Fighting Diet." (MD Anderson Cancer Center 2016) Texas Oncology, in another section of the website, discusses how "Eating a healthy diet and exercising regularly not only help you maintain your physical

strength, but also help keep your body strong for the fight." (Texas Oncology 2016) In this way, we can see that emphasis is placed on patients being "battle ready" through sustenance and nutrition. This type of strength is not the only type necessary for the fight ahead, though.

According to Texas Oncology, "Every patient is different and handles their disease in a way that is uniquely personal. Some are cancer warriors, others wish to keep quiet." (Texas Oncology 2016) People are unique in the way that they handle their cancer "battle," but all centers acknowledge that cancer is not just a physical, but a mental battle and people must be prepared for that battle. Patient testimonials often highlight this idea of mentally preparing for the fight.

According to one patient testimonial of a former military pilot on the Burzysnki Center's website, the patient "knew his military fighting days would be nothing compared to his fight to beat cancer." Though not as directly related to battle, the following statement form patient Phil Gonzalez at MD Anderson also illustrates this idea of mentally preparing to fight: "I never said, 'why me,'" Phil says. "I said, "We're going to kick this in the butt'." (MD Anderson Cancer Center 2016) Similarly, a former patient of Christus Spohn discusses her shift in mentality in her video testimonial on the website. The high school coach says, "What's stronger than cancer? Steel and that's my last name" as she discusses how she fought to overcome cancer. These sentiments are echoed in Texas Oncology's "I CAN Fight" campaign which features footage of cancer survivors giving advice to patients to help them win their battle with cancer. Indeed, the

description of the campaign and video states, “Many of our patients offer encouragement and strength by sharing their fighting words.” (Texas Oncology 2016)

In this battle, one must be brave. That kind of bravery is inspiring to others. This is illustrated in the following quote from Texas Oncology’s survivor page: “Completing cancer treatment is a badge of honor.” (Texas Oncology 2016) This implies that finishing the battle with cancer is honorable and to be commended. This idea is further represented in their Maverick Gameball Program. At each home game for the Mavericks, patients get to present the official game ball to the referees. “Each representative helps raise awareness of fighting cancer and is an inspiration to all the fans in attendance.” (Texas Oncology 2016)

However, patients battling cancer are not alone. According to Texas Oncology, “Every patient is surrounded by caregivers that stand with them in their cancer fight.” Patients are urged to utilize their resources by “engaging friends and family around” them and recognize that they “don’t have to face this fight alone.” (Texas Oncology 2016) Sometimes this can be done with immediate family and friends, other times they can utilize support groups like MD Anderson’s Cancer180 which lets young adults “know they are not alone in the fight by providing a social environment where young adult patients, survivors, caregivers, family and friends in their 20s and 30s can connect with other young adults affected by cancer.” This community, facilitated by the treatment center, can provide support in the patient’s cancer battle, just like caretakers can.

Caretakers are also urged to see the importance of their role in a patient's cancer battle. "In the fight against cancer, there's a place for everyone.(this line is repeated) With thoughtful choices that balance your interests, available time and resources, your cancer supporting role can make a difference in the life of patients, and in yours. (202) Through this, Texas Oncology emphasizes that caregivers find balance, but also understand the impact they have on their loved one's fight with cancer through their support.

Cancer analogy: journey

The idea that cancer is a journey is one that is repeated often throughout traditional treatment center websites, in particular. This idea is reiterated throughout the cancer treatment process, beginning at diagnosis. Indeed, MD Anderson states that "receiving a cancer diagnosis is a life-changing event. We are here for you every step of the way, as you or a loved one navigate the process from treatment to recovery." (MD Anderson Cancer Center 2016) In this way, this center is saying that cancer, from diagnosis to recovery, is a long arduous journey and they will be there to guide the patients all along the way, from it's very beginning.

Likewise, under their "Newly Diagnosed" section, Texas Oncology states that "Navigating the treatment process may seem overwhelming, but our compassionate staff will be by your side every step of the way. Use these resources as a starting point, but talk to us whenever you have questions. We're in this together." (Texas Oncology 2016) Again, cancer is portrayed is a journey that must be navigated and the staff will be there, all along the way, every step the patient takes, to guide them. To that end, this site, along

with others has “assembled a variety of tools, tips, and resources to help navigate many of the issues you are facing.”

One of the primary tools along this journey is the patient navigator, whose title alone implies that they are there to help patients find their way and that is essentially what they do. MD Anderson also has volunteers who aid patients in a similar way through something called My Cancer Connection. MD Anderson says about these volunteers, “myCancerConnection volunteers are here so that you don’t have to make the cancer journey by yourself.” (MD Anderson 2016) Texas Oncology also brings up the idea that caretakers are also part of this journey and making it with the patient: “helping a cancer patient on their journey can mean taking one of your own.” (202) In this way, the cancer journey is one that everyone makes together—not just the patient or the doctors. Once the treatment process is over, there is still a journey into survivorship as discussed by Texas Oncology, “A survivorship plan, a comprehensive roadmap for life after cancer, can bring order and structure,” (Texas Oncology 2016) which can provide the needed guidance along an otherwise uncertain path to resuming the life a patient had prior to cancer. Even after cancer, patients still need tools for navigation according to this analogy.

Cancer analogy: new normal

Though exactly not an analogy, there is another recurring theme on the websites for treatment centers that was also reflected in the physician and staff interviews. The idea of a “new normal” once a person is afflicted with cancer and goes through treatment is discussed. (Texas Oncology 2016) In fact, under the advice from experts section on

the Texas Oncology website, one of the repeated tidbits of information is that patients should “let (your) loved ones know treatment is finished and how they can help them (you) adapt to their (your) “new normal” (Texas Oncology 2016). Texas Oncology defines this “new normal” as a life and lifestyle as a cancer survivor, now that the treatment, energy and activity, along with the emotional support from friends and family, has dissipated. “With less frequent hands on care,” survivors can feel alone and uncertain and now have greater responsibility for managing the aspects of their lives after cancer. (Texas Oncology 2016) Again, an emphasis is placed on the patient as being responsible for themselves and their health and they are advised to continue screening, maintain healthy habits, watch for changes in their condition/health and communicate about how they are feeling and any changes they see.

MD Anderson defines the “new normal” as the state of a person after the physical and emotional changes caused by cancer or its treatment that “can linger for years or a lifetime.” (MD Anderson Cancer Center 2016) After treatment, although a person may be eager to get back to normal life, that may not be possible. However, these changes need not be all bad. As one former patient, Phil Gonzalez, said in his testimonial, “Cancer changed me. I see the beauty in all of this. I see life in a different perspective," he says. "I take my time with everything, including when it comes to meals. I'm always the last to finish, and I enjoy every bite. My quality of life has blossomed thanks to the doctors at MD Anderson.” (MD Anderson Cancer Center 2016) In Phil’s case, cancer and the doctors who treated him changed his outlook on life for the

better. He now has deeper appreciation for everything than he had before the cancer, back when things were "normal," rather than "new normal."

These analogies are intended to help to boost the morale of the patients at a time when they are under great physical and emotional duress. Patients can suffer from what medical professionals refer to as "decision fatigue" (an inability to make decisions due to being overwhelmed by their diagnosis and information surrounding their illness), so these analogies that provide a sense of camaraderie and structure, like the team and journey analogies can assist patients when they are feeling lost and alone. The battle analogy encourages patients to, again, take on the sick role and embrace the affiliated responsibility of doing everything possible to become well, in spite of any feelings of disillusionment that may come from the possible outcomes of a cancer diagnosis. This is especially critical in the face of treatment that is very difficult and unpleasant, such as traditional cancer treatment. Emphasizing that the patient is brave to fight makes them admirable and creating this sense that to fight is inspiring encourages them to stick with treatment, no matter how difficult it may be. Understanding that there is a "new normal" after cancer also helps legitimize the feelings that patients may struggle with after they are in remission, whether those are feelings of loneliness from no longer being surrounded by a team or feelings of frustration with not being exactly the same as they were prior to treatment. Having these feelings legitimized also provides patients with a sense of support and understanding from their physicians and thus, as a whole, all of these things help to fulfill that need for a supportive care environment, both in treatment and recovery.

While there is a great deal of overlap in the different kinds of sites and the ideas they portray, there are also differences that point out the distinctions between CAM and Traditional facilities.

Only traditional treatment center websites

Though Traditional and CAM facilities share many common types of information, images and ways of disseminating that information to support their patients, they also have distinct differences that lend to their unique identities as a particular branch of medicine. These differences are very pronounced and help establish which type of facility they are for the potential patient almost immediately upon first entering the website.

Traditional treatment centers websites appear very thorough in their discussion of cancer as a disease, the process of treatment and what happens after treatment. Traditional treatment center websites are all structured in a similar way. There is a narrative form that begins by telling of the process of being diagnosed, understanding what the diagnosis means, and dealing with it in a variety of contexts such as work, family life, with children, etc. They then discuss treatment options and complications and how to deal with that in those same contexts. They include fact sheets and information every step of the way for any part of cancer it might be necessary for, including things like information on how to cope with cancer, how to be a care taker, how to deal with role conflict, how to deal with grief and how to talk with family, friends, children and coworkers--even guidelines for how to be intimate during treatment. In comparison to the alternative treatment center websites which sometimes

refer back to the same American Cancer Association Fact Sheets that traditional treatment centers use, but typically only discuss the process of treatment and how it works, these websites read more like a guidebook and prepare the patient for every part of treatment, tell them how to get to the clinic, make them aware of accommodations available in the city and the facility when they arrive, what to do after they leave, how to cope with being a chronic patient (someone who has cancer more than once), and information about clinical trials. These websites are designed in such a way that patients have no need to look to any other resource. Thus, there is no need for patients to visit any other website or treatment center site, and, in case the amount of information online is overwhelming, these sites also provide patient navigators to help guide patients through their treatment process.

Patient navigators

Receiving a cancer diagnosis can be very challenging. Patients and their families may feel overwhelmed and uncertain about the next step. All the traditional treatment centers offer help with managing treatment and navigating hospital resources through a patient navigator. Although all traditional treatment centers mention that they have Patient Navigators, only the two religious affiliated sites actually discuss these services in detail. (Christus Spohn 2016, St Joseph Cancer Center 2016) Christus Spohn states that their goal is to guide patients through the cancer care process and support them through stressful situations by providing personalized help to overcome any hospital barriers. This process begins at diagnosis and continues through all phases of the "cancer experience." (Christus Spohn 2016) According to Christus Spohn, the duties of

the Patient Navigator include connecting patients to community resources, services and support; “guiding patients and their families through the complexities of the health care system” (Christus Spohn 2016); educating patients and helping patients understand their cancer treatment options; assisting with setting up appointments and transportation needs; providing referrals for nutrition information and acting as a liaison between patients and physicians; identifying financial assistance that can aid the patient and “providing patients with compassionate, ongoing support from diagnosis through treatment to survivorship.” (Christus Spohn 2016)

St. Joseph’s echoes these same sentiments in their purpose and duties, adding that they “maintain truly patient-centered” care through these services. (St Joseph Cancer Center 2016) Their patient navigator not only refers patients to nutritionists, but also Clergy, Physical Therapists, Palliative Care, Hospice Services and Social Workers. This team is lead by a physician and comes together to empower patients with the resources to manage their treatment process. The patient navigator is the liaison with the patient and this service is available at no charge to patients.

The patient navigator seems to fill the role that alternative treatment centers do when it comes to personalized patient centered care. One of the common complaints about traditional treatment centers is that they are impersonal due to the nature of the specialization of each person who plays a role in patient treatment and the large number of patients being seen on any given day. This lack of personal attention makes patients feel alienated and alone, but the patient navigator role seems to be an answer to this problem. No matter how many different technicians and specialists a patient may see,

patient navigators stay with them throughout the process so that there is always guidance, a person who is looking out for their best interests and someone who is consistently there for them throughout the treatment process, much like the role alternative practitioners take in care. In this way, it would seem that patient navigators are a role that was created with the intention of not only rectifying a perceived problem with traditional medicine, but a way to be competitive with alternative treatment centers. Proponents of alternative treatment centers often advocate for their type of medicine based on their small organization and the more personal relationship between physicians and patients. Because critics of traditional medicine tend to note this lack of time and attention to relationship with patients as leading to an unawareness of patient needs and feelings, the use of a person acting as a patient navigator allows traditional treatment centers to fill that void and attempt to rectify this problem, thus making them more competitive with alternative treatment centers when it comes to personalized care.

Support groups

While Alternative Treatment Centers make no mention of them, all Traditional Treatment Centers offer access to a variety of support groups. These support groups can help patients cope with various stages of the cancer process and, because people with cancer face not only physical and medical challenges, but also emotional reactions to their disease, connecting with other patients and survivors through support groups can provide a strong sense of comfort and emotional support. Support groups may help patients share cancer-related feelings and experiences that can help reduce stress and fear and feelings of isolation as well as offering the opportunity to gather more

information about current treatments and developments. According to studies, support groups can improve quality of life by "boosting self esteem, reducing depression and anxiety, and improving relationships with friends and family." (Christus Spohn 2016) Because each cancer patient or survivor and their loved ones have their own unique experience, the support groups available are geared toward a variety of people with varying purposes. Some groups are for bereavement, specific cancers, youth with Cancer, palliative care, Chinese (spoken language in the group is Mandarin), caregivers, family support groups, specific treatments, and children whose parents have cancer. For instance, one group at Christus Spohn called "Look Good…Feel Better"– is an American Cancer Society group that helps women deal with the appearance related side effects of cancer treatment. This group session is led by a trained local cosmetologist and women learn about cancer skin and nail care, as well as about wigs and scarves. Each woman receives a complementary tote of full-sized make-up and a wig fitting. Some of these groups are run by cancer survivors, some are run by medical professionals or, in this case, some other individual with relevant expertise to the group's needs.

Some sites like MD Anderson also offer special events like their week long Cancer Survivorship Conference which provides education to current and former patients, along with the opportunity to meet others like themselves. MD Anderson offers something similar for caregivers called Caregiver Week and also offers something called "Day Away," which are 6 hour field trips that take patients and caregivers away from their treatment and illness for just a day in order to experience life outside of cancer, briefly. For those who are unable to attend live support groups, conferences and activities, online

support and information is provided through a site called Warmnet. Warmnet also provides the opportunity to create care pages that update friends and family of patients about their progress and treatment in a general way.

While one alternative treatment center does have a separate website for patients to connect with one another and share their stories, they, along with all of the other alternative sites, do not have any mention of either support groups (live or via internet) or offer conferences and educational opportunities for patients and their families. This may be due to the fact that these centers are substantially smaller and, as such, have far fewer clients than these traditional treatment centers. Smaller numbers of clients may make it more difficult to start and sustain such a support group, but also may, in a way, make the support group a part of what they are already experiencing as a patient at a smaller facility. In a smaller facility, the patients and physicians may be in a more tightly knit group and, therefore, receive social support from one another. This is in contrast to the very large traditional treatment centers where patients may rarely have contact with one another and, therefore, are in greater need of something like a support group in order to provide people with these networks of social support and shared information. In fact the centers are so large that there is a wide enough variety of specific need with these support groups that there are almost as many varieties of support groups as there are resources for cancer patients and we can see the sort of compartmentalized structure of the treatment site and, as we will discuss later, treatment process, reflected in these support groups at this sites as well.

Volunteer

Traditional Treatment Centers also all offer the opportunity to for people to volunteer. Some sites simply make mention of the opportunity existing and leave contact information for those interested. Other sites like MD Anderson and Texas Oncology talk about the importance of volunteering as a rewarding experience and the potential for people to make a difference in the lives of others. Volunteers can donate blood or goods and services or even money. Outside of the personal sense of satisfaction a person might get from volunteering, they also get free parking, flu shots, cafeteria discounts, access to libraries and, at MD Anderson, the opportunity to attend a gala for volunteers.

Some sites, like Christus Spohn, have specific programs who they partner with that provide cancer related services for the community, such as First Friday, "a grassroots organization made up of women whose purpose is to knockout breast cancer through education, self-breast examination, and free screening mammograms for women who have no financial resources." (Christus Spohn 2016) and this group provides opportunities for people to volunteer, either separately from the hospital or at these First Friday screening events.

Other sites, like Texas Oncology, emphasize that "cancer is a medical, political, social, psychological, and economic issue that needs strong advocates" (Texas Oncology 2016) for appropriate legislative policies. "Every day, legislators and regulators make decisions that impact the lives of more than 14.5 million cancer survivors, their families, and all potential cancer patients." (TO 243) As such, it is important that cancer patients,

survivors, caregivers and friend and family members voice their opinions on legislation that effects quality cancer care and its affordability. "Texas Oncology supports legislation and policy that would save cancer patients money while eliminating barriers to high-quality, community-based cancer care" and, as such, they offer links to sites that allow patients, caregivers and volunteers to find opportunities that allow them to get involved in this aspect of cancer care. (Texas Oncology 2016)

These volunteer opportunities are presented in a way that makes them appealing to both the volunteer and the patient. Some of these volunteer opportunities highlight the fact that the hospital is in this fight for better care for patients with the patients. Particularly with the legislation opportunities, sites again put the responsibility back on the patient and their loved ones to take control, get involved, and do something to make a positive impact on what happens to the patients during treatment. These opportunities are not offered at alternative treatment sites because, again, there is a difference in the size of the facilities and the number of patients, which means that volunteers are likely not needed. These opportunities may be presented to the patients to appeal to the perceived shortcomings of the traditional branch of medicine by offering a sense of care and camaraderie that is more typical of alternative treatment centers. Putting an emphasis on patients, families and volunteers taking a role in legislation extends the idea of the importance of exiting the sick role and being as proactive as possible in treatment to trying to have an impact on policies that effect treatment and patients. To be a good patient is to be active in every possible part of the treatment process and the effort to exit the sick role, including making one's voice heard when it comes to public policy and

legislation that effects that treatment. There is no representation of alternative medicine, specifically, in this type of legislation or these fundraising and nonprofit groups. Traditional medicine, alone, is presented and alternative medicine is notably absent which speaks to the lack of legitimacy bestowed upon it by traditional medicine and mainstream society.

Bald patients

One image that is unique to traditional treatment centers is that of balding patients. One of the side effects of chemotherapy, a common traditional treatment for cancer, is hair loss. Because alternative treatment centers are proponents of avoiding chemotherapy and other traditional medicine treatments if at all possible, it makes sense that those sites do not portray images of patients who are going through hair loss or regrowth, while those sites that do utilize it, do show those images.

Images always show the patient smiling and apparently in good spirits, as in this photo below from MD Anderson (see Figure 28). The patient, smiling and bald, is being hugged by a friend or loved one while she lies in her hospital bed, presumably in good spirits.

Figure 28: Bald patient 1. Reprinted from MD Anderson Cancer Center (2016)

Similarly, the next image shows a very young child smiling in the arms of a woman in the entry way to the children's center at MD Anderson (see Figure 29). There is no indication that either of these patients are suffering and both appear to be happy and well cared for.

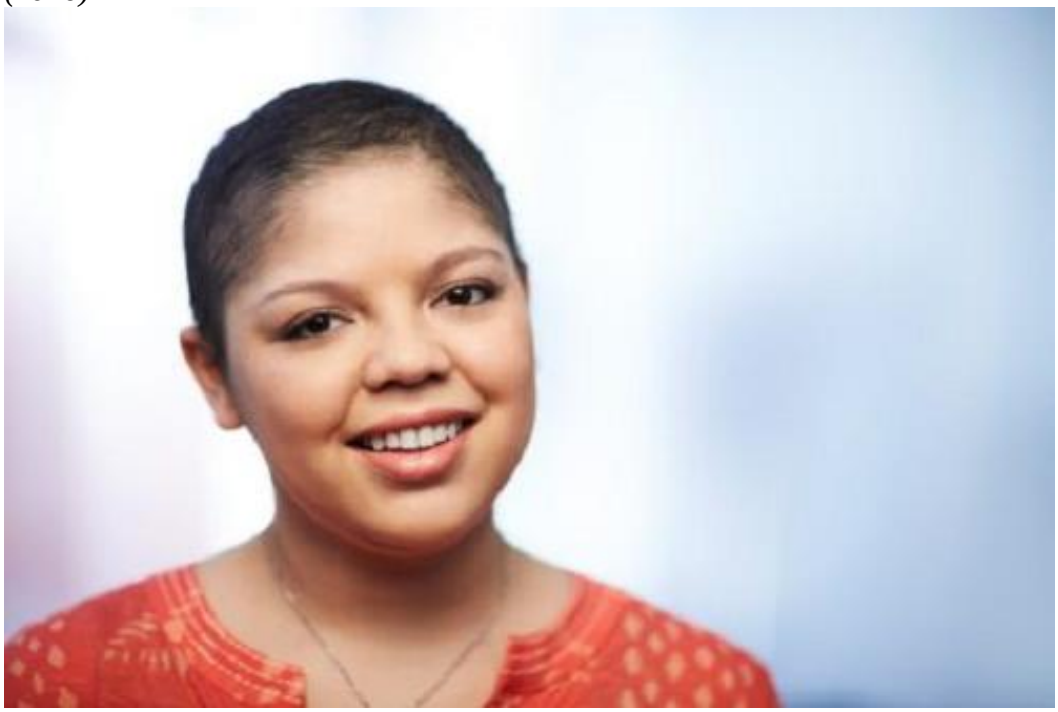
Figure 29: Bald patient 2. Reprinted from MD Anderson Cancer Center (2016)

MD Anderson also offers an onsite wig and beauty shop where people can style their hair, cut it, be fitted for and purchase wigs and scarves or other head wraps. They make it convenient for women to find solutions to this temporary problem of hair loss and to find sources of education on the best ways to handle and disguise it. The photo below (see Figure 30) depicts the shop and it's services and demonstrates the accessibility of these options.

Figure 30: Wig shop. Reprinted from (MD Anderson Cancer Center 2016)

Finally, one of the survivor photos shows a young woman whose hair is very short and in the process of beginning to grow back (see Figure 31). In the photo she is smiling and, in her testimonial, she talks about learning to find herself beautiful during cancer and it's treatment process. She is an attractive woman and the photo and the ideas expressed, in conjunction with the other photos, portray the idea that hair loss is not so bad and does not have to be the end of beauty for female patients undergoing chemotherapy.

Figure 31: Bald survivor. Reprinted from MD Anderson Cancer Treatment Center (2016)



These depictions of women dealing with the hair loss brought on by chemotherapy are meant to normalize it for patients and make them feel comfortable with the prospect of one of the most well-known side effects of traditional cancer treatment—we don't see these depictions in alternative medicine because the treatment that causes hair loss is not utilized at those centers. As previously stated, the sites make it seem like it is not all that bad and provide a great deal of resources for adjusting to this physical change. The information is meant for clients to come to terms with the idea of hair loss . Once again, this seems as though it is meant to help attract patients, especially if they are deterred by the idea of losing their hair.

Guest Quarters and Education/Residency Opportunities

Due to size, another feature that only traditional treatment centers offer is onsite accommodations. Guests are able to stay on the hospital grounds in these quarters. MD Anderson's Rotary House (MD Anderson Cancer Center 2016) has services much like that of a hotel, including room service. Christus Spohn's Kieshnick Guest House is described as a special "home away from home" for families who have loved ones in the hospital and is located across the street, with 21 guestrooms with private baths and access to a central living room. The Guest House, pictured below (see Figure 32), is provided as a community service for families at minimal donation of $25 a night. (Christus Spohn 2016)

Figure 32: Guest house. Reprinted from Christus Spohn Health System (2016)

Another comment that is only seen on the websites of traditional treatment centers is the opportunity for medical residencies or internships. MD Anderson is a teaching hospital, and, as such, offers many opportunities for medical students and

aspiring medical professionals to complete training there. All traditional websites feature links to learning more about these opportunities and information about completing education and training at their sites. Because alternative medicine does not require residencies of this sort, that type of information is not on their sites. Because these sites do not have education of medical professionals as part of their identity, this is not a priority and, instead, that energy is devoted to educating only the patients about their specific methods and treatment options, which are quite different from those of traditional treatment centers.

Only alternative treatment center websites

Principals of holistic medicine

Alternative websites uniquely utilize Naturopathic medicine and state that their practice is based on the tenets of naturopathic and holistic medicine. There are different types of naturopathic medicine and the sites that utilize a more specific type explain their methods and how they fall in line with naturopathic medicine or compare to traditional medicine. They often dedicate at least a paragraph, if not a page, on their site to defining and explaining this type of medicine and its principle (previously discussed in the literature review.)

A comprehensive definition of naturopathic medicine, based on these alternative treatment center websites, refers to naturopathic medicine as "a system of medicine based on the healing power of nature, prevention, and non-invasive, natural therapeutics" (Health Blossoms 2016) Innovations Wellness Center contributes the idea of a blending of old and new medicine to the definition of naturopathic medicine,

stating, “Naturopathic medicine blends centuries-old natural, non-toxic therapies with current advances in the study of health and human systems, covering all aspects of family health from prenatal to geriatric care.” (Innovations Wellness Center 2016) Health Blossoms echoes this sentiment stating, “It (naturopathic medicine) is as old as healing itself and as new as today’s medical breakthroughs.”

This approach allows practitioners to support the body’s innate healing capacity through the use of natural remedies and also allows physicians to empower patients to make dietary and lifestyle changes that address and prevent disease. Aside from being natural, they particularly emphasize that medicine is personalized, “concentrates on whole-patient wellness” and is focused on self-care and prevention. Naturopathic physicians cooperate with all other branches of medical science referring patients to other practitioners for diagnosis or treatment when appropriate.

Naturopathic medicine is defined by principles rather than by methods or modalities. There are 6 principles of naturopathic philosophy, which are all encompassed in the definitions of naturopathic medicine on these websites. Nature Blossoms, Innovations Wellness Center and Integrative Functional Health Center also take the time to list and explain these principles, and the first tenet “First, do no harm,” is actually part of the Burzynski clinic’s logo. These tenets and their explanations can be seen in the table below (see Figure 33).

Figure 33: Table of alternative medicine tenets

Principle	Explanation
First, do no Harm	physicians should try to minimize the risk of harmful side effects by utilizing the most natural and least invasive therapy
Identify and Treat the Cause	refers to treating the cause to the patient's illness, rather than focusing on suppressing the symptoms
Healing Power of Nature	trust in the body's inherent wisdom to heal itself
Treat the whole person	refers to the view of the body as an integrated whole that includes physical, mental, emotional, and spiritual dimensions
Doctor as Teacher	calls for practitioners to encourage patients to take responsibility for their health by educating them in the steps to achieving and maintaining health through dietary and lifestyle changes
Prevention	assessment of heredity, risk factors, and susceptibility to disease in order to prevent illness

All of these ideas are apparent, whether explicitly stated or not, throughout the websites of the alternative treatment centers. These tenets are central to the identity of these clinics and, as such, are central features of their websites. These guidelines are unique to alternative treatment centers and there is nothing similar in traditional medicine, or likewise, their treatment center websites. The religious affiliated traditional centers have mission statements, but this is the only thing similar to these ideals that we see on their websites. This may be because it is a philosophy or underlying belief

system that shapes these principals and, typically, traditional medicine is grounded in science and rational thinking, distancing itself from these sorts of ideals.

Images of Eastern Medicine

While there are many references to Naturopathic medicine, there are very few images that actually depict it in the same way that we see traditional medicine being depicted with the stereotypical representations of what people perceive medicine to be. Most of the alternative treatment centers focus on images of nature, which is, to an extent, shared with traditional treatment centers, although they are used in slightly different ways. However, one type of image that only alternative treatment centers utilize are images of Traditional Chinese Medicine, or TCM. The facility Health Blossoms takes the time to not only explain naturopathic medicine, but to also explain Traditional Chinese Medicine (TCM) as having been practiced for over 4,000 years and having a similar philosophy to naturopathic medicine.

Practitioners of TCM "look for the root cause of disharmony in the body" and "individuals are viewed as unique and how disease manifests is unique to them." (Health Blossoms 2016) This translates into different patterns for the same disease and different treatments. When treatments are individualized, there is better clinical success." This idea is very similar to the ideas of naturopathic medicine. TCM practitioners usually don't rely on the same diagnostic tools as Western medical practitioners and use a variety of modalities to treat disease including acupuncture, Chinese herbs, cupping, moxibustion, acupressure, and nutrition.

The following images of parchment paper and herbs with mandarin scrawled on it (see Figure 34) and another with acupuncture needles and blueberries (see Figure 35) found in the rolling header for this center seem to emphasize this idea that this method has been around for a long time, but is not antiquated. Rather, the fact that it has been around for so long is evidence that it works. They also show some of the modalities: nutrition, as illustrated by the berries, and Chinese herbs and acupuncture needles.

Figure 34: Herbs and scroll. Reprinted from Health Blossoms (2016)

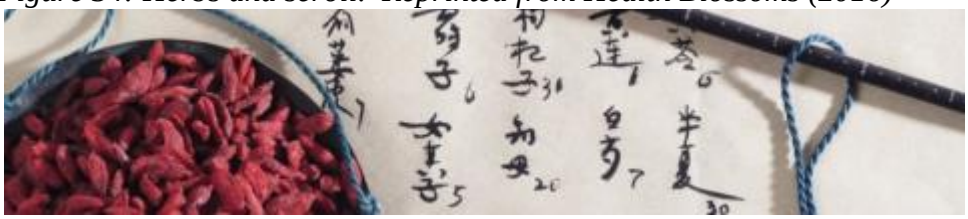


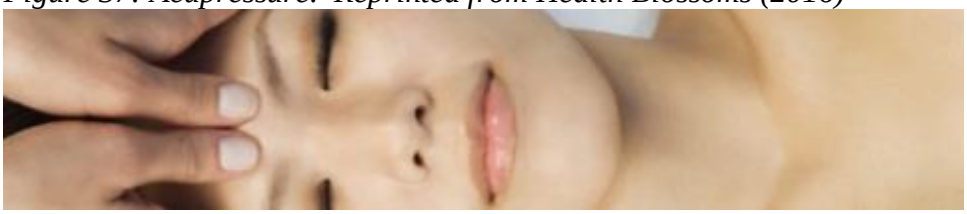
Figure 35: Blueberries and scroll. Reprinted from Health Blossoms (2016)

Beyond that, the images have a certain sense of serenity to them. This is more pronounced in two more of the header photos depicting acupuncture, one depicting a relaxed woman's face with a person placing acupuncture needles (see Figure 36) and another depicting a relaxed woman's face with a person holding a single acupuncture needle at center of forehead.

Figure 36: Acupuncture. Reprinted from Health Blossoms (2016)

Yet another header photo, this time of a woman with thumbs pressed to the center of her forehead by another person depicts a woman who looks relaxed, almost like she is getting a massage (see Figure 37). This image, presumed to be depicting another modality, acupressure, evokes an even stronger sense of relaxation and restoration, which, after all is one of the goals of treatment: to restore the body to its natural state.

Figure 37: Acupressure. Reprinted from Health Blossoms (2016)



A final image of this sort is yet another header photo, this time showing 2 hands palm up, one under other (see Figure 38). The hands are female hands and they look gentle and healing. This would, again, be an ideal image to convey, given that this is likely to be intended to portray another modality—cupping—which should be a healing treatment.

Figure 38: Cupping. Reprinted from Health Blossoms (2016)

Not only do these images convey Eastern medicine, they also convey a sense of peace and relaxation. These sorts of images are commonly tied to not only Eastern medicine, but also Naturopathic medicine, perhaps because Eastern medicine is a type of Naturopathic medicine and very well known. When these images are seen in outside media, they are also often related to spas and Feng shui. Interestingly, Innovations Wellness Center, another alternative treatment center, boasts on their site that their facility is "compliant with the concepts of feng shui and "green architecture" and boasts an atmosphere that includes full spectrum lighting, features to minimize electromagnetic stress, organic paint, and non-toxic flooring, furniture, and fixtures. This exquisitely designed facility includes a full-service medical center and an alternative medicine department with state-of-the-art exam and procedure rooms." (Innovations Wellness Center 2016) The focus is on the environment being soothing and is presented in such a

way that it almost sounds like a brochure for a resort. The implication is that the space people seek treatment in should be calming and, ultimately, surroundings matter.

A noticeable pattern among these images is not only this depiction of the sort of calm and soothing environment that Innovations Wellness Center uses, but the use of the color white. In these photos, it is mostly the empty space around the primary image. In the subject we will turn to next, the color white is used on the subject of the photo, itself.

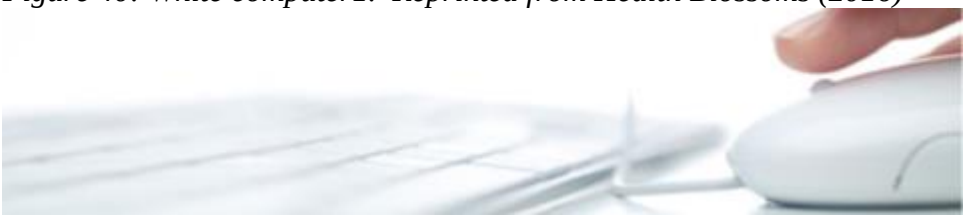
The color white

The color white is seen not only in the surrounding space in the images on alternative treatment center's websites, but also on the objects or people that are the focal point of the photo. This header photo on Health Blossom's website (see Figure 39) depicts again, a white background, but also a white porcelain mortar and pestle with some transparent and white pills in the foreground.

Figure 39. White mortar and pestle. Reprinted from Health Blossoms (2016)

This use of white is not limited to tools affiliated with herbs and supplements, though. White is also used in pictures of computers, as seen in this header photo of a keyboard and mouse, both white, on a white background (see Figure 40).

Figure 40: White computer1. Reprinted from Health Blossoms (2016)



Innovations Wellness Center also does this, not only with the computer, keyboard, mouse, desk and background (see Figure 41), but also, as you can see in another photo from their website, on the clothing of the people using the computer (see Figure 42).

Figure 41: White computer 2. Reprinted from Innovations Wellness Center (2016)

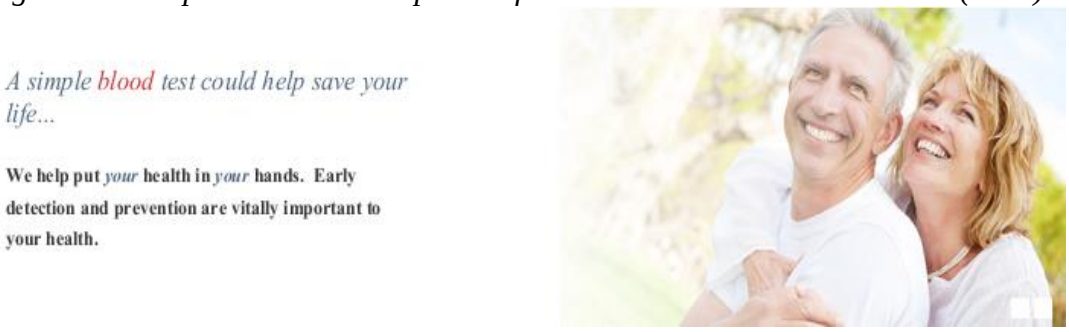
Figure 42: White couple on white computer. Reprinted from Innovations Wellness Center (2016)

Both individuals comprising the couple using the computer are wearing white. Images of couples wearing white are also used quite frequently on these sites as seen below in these images from Energy Health Centre (see Figure 43) and Innovations

Wellness Center (see Figure 44). The images are from two different sites, but it is difficult not to notice the striking similarities between the photos, in general, and the couples themselves—both white, the man older with greying hair and the woman looking slightly younger with blonde hair. All of the couples look healthy and happy.

Figure 43: Couple in white 1. Reprinted from Energy Health Centre (2014)

Figure 44: Couple in white 2. Reprinted from Innovations Wellness Center (2016)



The people wearing white are not always part of a couple. Sometimes, they are by themselves, too, as seen in this image from Innovations Wellness Center of a woman, wearing a white dress, hat and scarf, running on a beach (see Figure 45).

Figure 45: Woman in white on beach. Reprinted from Innovations Wellness Center (2016)

It is difficult to speculate about the exact meaning behind all the use of white in these photos since there is no specific meaning of the color in holistic or naturopathic medicine. In Feng shui it is said to represent purity and new beginnings and in popular culture it is also said to signify peace. Regardless of the intended purpose of the use of the color, the way the images are presented seem to indicate an environment that is relaxing, restorative and clean, and people who are healthy and happy. It does seem to evoke a feeling of peace and creates images of treatment modalities that appear pleasant and a place that is warm and inviting. These images also have a notable lack of diversity with respect to sexuality and race. All images depict only straight white couples or single white individuals, who also all happen to be wearing white, all of whom appear to be of higher socioeconomic status. Seeing as how these are stock photos rather than

photos of actual patients, the implication is that white and heterosexual is the norm. Such images, either purposely or not, could potentially negatively impact individuals who are not heterosexual or white or higher socioeconomic status and their decision to visit these clinics based on the idea that this particular treatment center or type of medicine is not accepting of who they are and therefore not for them. The use of these particular photos does also make it seem as though the target demographic for these alternative treatment facilities upper income Whites. It is possible that this is intentional due to the fact that people who have higher socioeconomic status are more likely to be able to afford these treatments since they are typically not covered by insurance and must be paid for out of pocket. The majority of higher socioeconomic status individuals are white, so if these centers have figured out that these are the individuals who are most likely to utilize their services, it is understandable that they might choose to utilize materials that might appeal to that demographic. However, as previously mentioned, this runs the risk of alienating the individuals who do not share those characteristics and thus, may also have the effect of perpetuating the same demographic using their facilities, with little to no variation.

Alternative treatment center biographies

Similar to the traditional websites, the websites of alternative treatment centers feature practitioner bios. While these biographies are similar in that they include employment history and educational institutions, they are also different in a few respects. Some are more formal and, when they list education and employment, it is not uncommon for listings to include the age at which the practitioner graduated, the rank in

their class and publications. Louisa Williams of Austin Naturopath mentions that she was on the Dean's list and started in Psychology, graduated cum laude from Texas Chiropractic College and has authored a book along with several teaching manuals and research articles. (Austin Naturopath 2016) Similarly, Burzysnki discusses his age at graduations and graduating rank along with the fact that he has had over 8000 patients. He also shares the number of publications he has had (300) and talks about the fact that he has coauthored with physicians at MD Anderson. He currently has 242 patients in 35 countries and 17 proprietary scientific inventions as of January 2011. (Burzynski Clinic 2016) These additions add to the list of degrees that are standard for traditional websites. These biographies are also, at times, less formal, sometimes including snippets of information about their personal lives.

For instance, biographies are sometimes written in first person. Instead of reading as a resume, these read like a personal narrative. In the case of Nature Blossom's Kathryn Mackenzie, the narrative begins with her stating jovially about how she originally wanted to be a dentist, which led her to major in biology and health sciences. During an intern program for students planning to pursue a career as a dentist, she realized dentistry wasn't really for her, but knew she still wanted a career in health care. Simultaneously, her mother's health declined. Based on her bloodwork, her mother's doctors said she was healthy, so her mother sought a 2nd opinion. When she sought a second opinion, her care team of a holistic medicine doctor, an acupuncturist and a homeopath determined that she had chronic fatigue and guided her to improvement in her health. Mackenzie was intrigued, so she went with her mother to her appointments,

did some research, and determined that this was what she wanted to pursue. Her new goal was to “become a health practitioner that spends time with their patients, teaches them how to eat and live better and offers noninvasive therapies.” As she states in her biography, she “is in an ongoing journey for optimal health,” herself, and she feels “it is important to be an example of how holistic health care, a healthy diet and exercise can be powerfully beneficial to health” one feels much more connected to the passion of what she has written than the laundry list of degrees and third person resumes of career experience.

While none of the other bios are written in first person, many of them do capture some of the same spirit and ideals as Dr. Mackenzie in their content. It is very common in these physicians’ biographies to find a sort of philosophy, if you will, on the way patients should be treated and approached interwoven with the particular methodologies they utilize. It is also common to see some mention of the way that traditional medicine has failed. For instance, Layne Sebring of the Sebring Clinic in Wimberly has 20 years of experience treating patients with his nutrition/paleo-based practice and says that he specializes in "treating people modern medicine has failed, respecting membership in the human race and our shared genetics." (Sebring Clinic 2016) In this way, the Alternative websites focus on how Alternative medicine provided answers while Traditional methods could not.

Another distinction between traditional and alternative biographies relates to powerful “discovery” stories.. For example, Dr. Sebring says that through his methods, he has answers to treating and reversing chronic disease, such as heart disease, chronic

fatigue, hypothyroidism, diabetes, anxiety, depression, auto-immune disease and heavy metal toxicity. Similarly, in his biography, Burzinsky discusses his discovery of the beginning of his method in 1967, when he identified naturally occurring peptides in the human body and concluded they could control cancer growth. He then found a deficiency of these peptides in cancer patients, which inspired the treatment method that he has now obtained FDA approval for and utilizes at his clinic.

Alternative practitioner's biographies often include a discussion of how the physicians started practicing alternative medicine and their philosophy, when it comes to treating patients, their methods, and occasionally, a little bit about their personal lives. Ultimately, these differences might be seen as offering a more personal and human element to the only direct introduction to physicians that exists on such websites. The fact that alternative treatment centers have so much more information about practitioners as humans might be a draw to consumers of health care services and might be seen as a benefit to utilizing this type of medicine.

Prominent themes

Images of nature

While traditional cancer treatment centers utilize a great deal of visual representation for the technology they possess, alternative treatment centers frequently use nature in their photos. In fact, many of the logos these centers use either depict plants or flowers in them, visually, or in the name itself.

Though the alternative treatment center, Health Blossoms, has no logo, it literally uses a nature reference in its name and in a tagline on its home page: "Make an

appointment and learn how acupuncture and natural medicine may help your health blossom." Other alternative treatment centers visually represent nature or plants in their logos. The logo for Integrative Functional Health Center features a Caduceus, which is commonly seen as medical symbol. In traditional medicine, this symbol is a winged staff with 2 snakes weaving around it. In contrast, the one featured as part of the logo of Integrative Functional Health Center is green and features 2 flowering vines with large leaves at the top, where the wings would normally be (see Figure 46).

Figure 46: Alternative logo 1. Reprinted from Integrative and Functional Health Center (2015)

Similarly, Energy Health Center's logo is their clinic name in blue, over a green lily pad with pink lotus flower on top (see Figure 47).

Figure 47: Alternative logo 2. Reprinted from Energy Health Centre (2014)

Health Blossoms' home page features a scrolling header photo behind the clinic name that changes every few seconds. The first featured photo is of lavender flowers among overturned glass pill bottles with their contents spilling out (see Figure 48). There is a similar photo in the scrolling header, only there is only one flower this time and it is gold (see Figure 49), while yet another photo is of the green leaves on a branch (see Figure 50).

Figure 48: Pills and flowers 1. Reprinted from Health Blossoms (2016)

Figure 49: Pills and flowers 2. Reprinted from Health Blossoms (2016)

Figure 50: Branch. Reprinted from Health Blossoms (2016)

Many of these centers utilize the same company, Emerson Ecologics, for supplements, herbs, etc that their patients order. The logo is shades of green and includes a small leaf and is mostly just featured in a corner or link somewhere (see Figure 51).

Figure 51: Emerson logo. Reprinted from Innovations Wellness Center (2016)

Integrative and Functional Medicine Center, however, features a larger advertisement which shows not just the small leaf and green logo, but an entire background of leaves on trees (see Figure 52).

Figure 52: Emerson advertisement. Reprinted from Integrative and Functional Medicine Center (2015)

Even when the clinics carry their own supplements or have a pharmacy on site, this theme of nature persists. Energy Health Centre carries in house supplements and their bottles feature labels that have only the clinic name, rather than the full logo, but there is still green leaf as part of it (see Figure 53).

Figure 53: Supplements. Reprinted from Energy Health Centre (2014)

The Sebring Clinic in Wimberly has their own Paleo Pharmacy, and the sign is made from natural materials—branches and a rock with the words "Paleo Pharmacy" etched into it (see Figure 54).

Figure 54: Paleo pharmacy. Reprinted from Sebring Clinic (2016)

Much like the pharmacy sign, the pharmacy and clinic itself at this particular site, The Sebring Clinic, are made from more earthy seeming materials. The buildings are log and stone cabins, nestled among the trees (see Figure 55).

Figure 55 Alternative clinic 1. Reprinted from Sebring Clinic (2016)

These facilities can be seen in the background of photos of the physician, who is also, at one point, pictured holding a dog's face in his hands and kissing it on the forehead (see Figure 56), and the photos of the facilities, themselves.

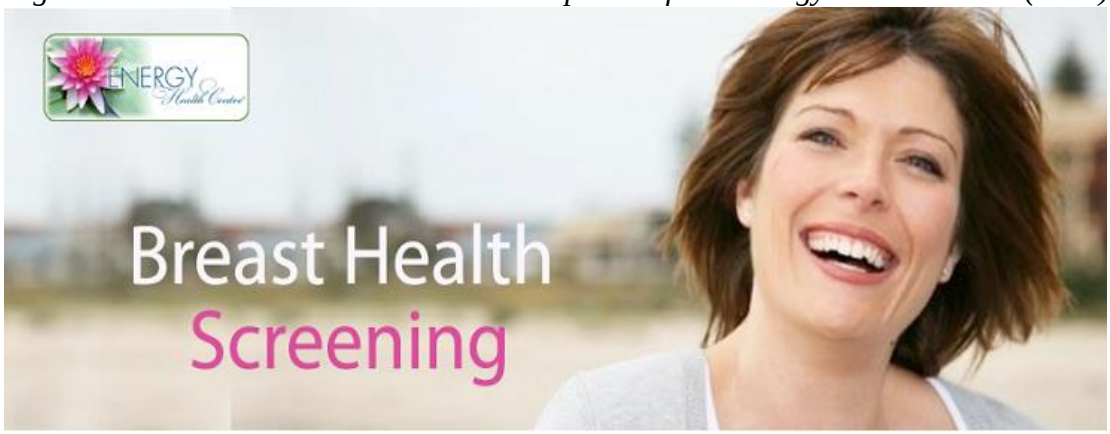
Figure 56: Physician and dog. Reprinted from Sebring Clinic (2016)

The website features a video with patient testimonials and one patient discusses the fact that he feels that the clinic is like a little resort, back in the trees, surrounded by of waterfalls and is much different from the sterile environment of a traditional medicine clinic. Similarly, in one of the few photos of another alternative center's exterior, the face of the building is wood and stone and presents a more natural looking, homey appearance (see Figure 57).

Figure 57: Alternative clinic 2. Reprinted from Integrative and Functional Health Center (2015)

These centers do place references to nature in places other than their logos, buildings and pharmacies/supplements, as well. Many of these sites feature header photos of people on a beach or among the trees (Innovations Wellness Centre 2016, Nature Blossoms 2016, Integrative Functional Health Center 2016) or as animations for other services/products (see Figure 58).

Figure 58: Woman in white on beach 2. Reprinted from Energy Health Centre (2014)

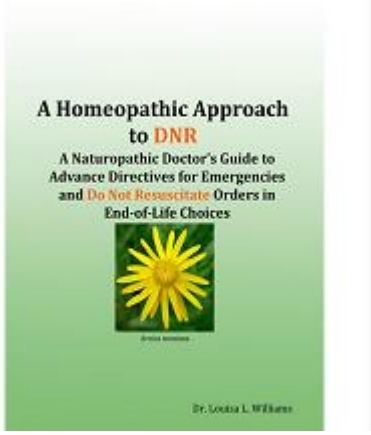


For example, Austin Naturopath utilizes an illustration of a leaf above their link to "naturopathic tips" and the cover of 2 of the books authored by the physician on site

(which are also advertised on the website) feature the silhouette of a tree on one (Radical Medicine, see Figure 59) and a photo of a daisy on another (Naturopathic approach to DNR, see Figure 60).

Figure 59: Book cover 1. Reprinted from Austin Naturopathic Medicine (2016)

Figure 60: Book cover 2. Reprinted from Austin Naturopathic Medicine (2016)



At times, traditional treatment sites will use images of nature, but it is not the most prevalent in the images. For example, Texas Oncology's home page features a photo of a large field of bluebonnets near a lake (see Figure 61) and also has quite a few photos of patients smiling, outdoors, with trees and plants in the background.

Figure 61: Bluebonnets. Reprinted from Texas Oncology (2016)

A photo of St. Joseph's hospital depicts a few trees in the front of the hospital building (see Figure 62).

Figure 62: Traditional treatment center 1. Reprinted from CHI St Joseph Health Center (2016)

Much like Texas Oncology, Christus Spohn has photo of a man with a dog outdoors with green grass and wildflowers visible (see Figure 63).

Figure 63: Patient and dog. Reprinted from Christus Spohn Health System (2016)

Further investigation reveals that these photos of people are, in fact, all photos of patients who received care at these facilities. Because the photos are of patients, rather than the physician or the logos/products the center offers, it would appear that the message they are attempting to convey is different. While the alternative centers are attempting to convey a message of natural medicine and communing with nature, it would appear that the traditional centers are attempting to use nature to convey happiness and, perhaps, a return to normalcy, since all of the photos are of patients who are now in remission. Similarly, MD Anderson only portrays nature in one way: there are two photos of flowers as received by patients—one shows a patient's hand with a hospital band who is also wearing a gown and the other shows flowers on the front desk of the hospital (see Figure 64).

Figure 64: Desk flowers. Reprinted from MD Anderson Cancer Center (2016)

In these depictions, flowers appear to be signs of care and nurturing as they are only used as gifts or decorations. A deeper exploration of the website does show that there are other depictions of nature, though they are human made. There is an entire page devoted to parks and gardens where a list and description (along with a few photos, see Figure 65 and Figure 66) of all of the gardens and structures in and around the hospital, along with their location. At the top of the page, the text says that, “even a little contact with nature can help raise people's spirits and put them at ease” and goes on to say “that is why MD Anderson has developed several green spaces where patients and caregivers can relax and enjoy a little bit of nature.”

Figure 65: Traditional center fountain. Reprinted from MD Anderson Cancer Center (2016)

Figure 66: Traditional center garden. Reprinted from MD Anderson Cancer Center (2016)

Texas Oncology seems to have chosen their home page photo based on the idea that they are an organization in Texas and the state flower of Texas is the bluebonnet. In addition, the photo is quite striking and certainly more likely to hold the viewer's attention than the typical shot of the outside of a hospital building.

The depiction of nature in Alternative treatment center sites goes along with the tenets of the type of medicine being practiced. Indeed, this idea of using the healing power of nature to remedy ailments is repeated in the discussion about the particular medicine/methods utilized by each site. For instance, the Burzynski clinic uses Antineoplastons, which are naturally occurring peptides in the body that do not damage healthy cells because they are already in the body, as opposed to radiation, which harms both cancer cells and healthy cells. All of the alternative treatment centers discuss how their supplements come from natural sources, which makes them higher quality and, in turn, more effective than those that are store bought. Therefore, these sites show photos of nature and natural elements to connect to this idea that they are attempting to stay connected to the body's natural state. Images of primitive buildings and signs surrounded by trees and nature appear to be more closely connected with these ideals than images of glass and metal buildings surrounded by cement. Nature has a healing power that is superior to artificial and foreign substances, which are viewed as more harmful to the body. This power is utilized by the physicians at these sites and is a recurring theme throughout not only the images, but the written messages conveyed on these websites

In contrast to alternative treatment centers which contain images of and references to nature, traditional treatment centers logos contain nothing related to nature. They contain straightforward text, sometimes with an emblem of some kind, sometimes without. The two centers that are affiliated with religious beliefs have logos that contain their name and an emblem that resembles a cross. Christus Spohn, who refer to themselves as a "Catholic health ministry" have a purple logo that simply reads "Christus Spohn Health System" and, to the left of the text, there is a purple, very square-shaped, cross the resembles the American Red Cross with lavender and white curvy lines coming across and off of it (see Figure 67).

Figure 67: Traditional center logo 1. Reprinted from Christus Spohn Health System (2016)

On their website, Christus Spohn discusses the meaning of their symbol. It "reflects the healing ministry of Jesus Christ-a combination of a medical cross and a religious cross. The flowing banner on the cross is a common symbol of the risen Christ, while the royal purple signifies Christ. The flowing banner also conveys a sense of motion as we move forward into a new era of service to our communities." (Christus Spohn 2016)

"Extending the healing ministry of Jesus, the St. Joseph Health System reflects God's love and compassion by providing excellent healthcare," and has a dark blue logo

that states “CHI St Joseph Health System.” To the left of the logo, there are four blocks of different blue and green colors, set into a diamond shape (see Figure 68). The white space in between those blocks creates a thin cross shape that also resembles the star of David. Unlike the Christus Spohn logo, however, the St Joseph’s logo has a tagline beneath the center name. In lighter blue, the text reads, “Imagine Better Health.”

Figure 68: Traditional center logo 2. Reprinted from CHI St Joseph Health Center (2016)

Similarly, Texas Oncology (which has no religious affiliation) has a tagline. The way their center name is presented almost resembles the Texas flag (see Figure 69). In red is the word “Texas,” then a gold star, then in blue, the word “Oncology.” Underneath those words, there is a line. Beneath the line, the text reads, “More breakthroughs. More victories.”

Figure 69: Traditional center logo 3. Reprinted from Texas Oncology (2016)

Most simplistic of all is the MD Anderson logo (see Figure 70). It simply reads (in all black text), very tiny on top "The University of Texas," beneath that, in larger print, "M.D. Anderson," and beneath that "Cancer Center." In red, there is a single line strike though of the word "cancer." This strikethrough of the word "Cancer" is indicative of what the center plans to do to cancer: eliminate and eradicate the disease.

Figure 70: Traditional center logo 4. Reprinted from Texas Oncology (2016)

However there is one alternative treatment center whose logo bears a closer resemblance to the traditional treatment centers than the nontraditional treatment centers. The Burzysnki clinic has a logo that does not feature any images of nature. Instead, the logo features the clinic name in white on blocks of red and blue. Beneath the clinic name is a tagline, "First, Do No Harm!" which is one of the six principles of Naturopathic philosophy. To the left of the clinic name, there is a globe and, forming a ring around the globe is a double helix dna strand (see Figure 71). The double helix is often tied to images of science. This particular logo is interesting because, while it is certainly acknowledging the principles of naturopathic medicine, it is also using the logo style of traditional treatment centers and embracing images commonly reflected in science and traditional medicine, such as the double helix.

Figure 71: Alternative center logo 3. Reprinted from Burzynski Clinic (2016)

In fact, their entire website has a striking lack of pictures, relative to all of the other sites. The pictures they have are of the physicians, the patients who give testimonies and one photo of the center (see Figure 72), which bears a striking resemblance to the photos we will soon see of the traditional treatment centers.

Figure 72: Alternative clinic 3. Reprinted from Burzynski Clinic (2016)

One reason these similarities are of particular interest is the fact that this particular clinic has been alternative, but has gone through the process of utilizing clinical trials with their method and getting FDA approval (something that other alternative treatment centers do not have) so that, in effect, they are going to be classified as traditional medicine rather than alternative. Thus, the similarity of their site

to those of traditional treatment centers could be a reflection of the changing market of their customers and who they are trying to appeal to.

Images of science, technology and innovation

While the traditional centers do contain some images of nature, as previously mentioned, they are not nearly as prominent or plentiful as they are in the alternative sites. Besides the photos of survivors and previous patients, nature makes an appearance, though very small, in the photos of the traditional treatment centers themselves. However, rather than a center that is located in the midst of trees or made from natural materials, there are generally only a couple of trees in the photo which features a large building made of steel and glass, as pictured in this image at the top of Texas Oncology's proton therapy page (see Figure 74).

Figure 73: Proton therapy center. Reprinted from Texas Oncology (2016)

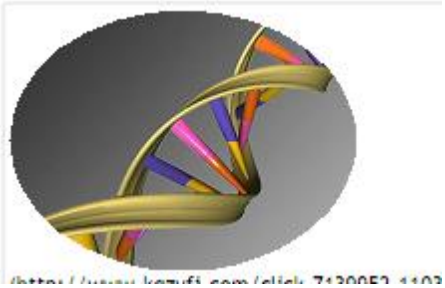
Photos of the traditional centers often depict the outside of the structures as being predominantly metal and glass, as seen in this rolling banner photo for St. Joseph's (see Figure 74)

Figure 74: Traditional treatment center 2. Reprinted from CHI St Joseph Health Center (2016)

These are in stark contrast to the alternative treatment center photos, previously shown.

As opposed to images of nature, images that depict science and technology are more plentiful in traditional treatment center sites. One such image is the image of the double helix/DNA strand, which is repeated quite often, both in traditional treatment center websites and nontraditional treatment center websites. The image is often associated with science and genetics, as seen here, in this photo on the alternative site, Innovations Wellness Center, near information about genetic testing (see Figure 75).

Figure 75: DNA strand. Reprinted from Innovations Wellness Center (2016)



On MD Anderson's website, the following image (see Figure 76) presents itself under the topic of genetic screening for hereditary cancers.

Figure 76: DNA strand profile. Reprinted from MD Anderson Cancer Center (2016)

Here we see the DNA strand with an image of a man's face/side profile over it. This seems to be some attempt to tie the piece of genetic material to a human and, perhaps, to drive home the idea that your DNA/genetics should be something that you are mindful of when it comes to cancer screening.

Under Texas Oncology's Research and Clinical Trials portion of their site, they feature an image depicting a female medical professional wearing safety goggles and gloves, holding up a glass slide which has digital images of DNA strands and a double helix (see Figure 77).

Figure 77: DNA slide. Reprinted from Texas Oncology (2016)

Likewise, the testing site for blood work and lab analysis for the alternative center, Integrative Functional Health Center, utilizes the following logo, which again depicts that image of a double helix (see Figure 78).

Figure 78: DNA logo. Reprinted from Integrative Functional Health Center (2015)

For these websites, it seems that the double helix is tied to the idea of research and lab work, which usually involves some sort of blood analysis. Therefore, it makes sense that these sections of the websites would incorporate images of people in a lab or materials that you would see in a lab. This is true for several sites, including MD Anderson. Under the section of their site titled "Research Areas", there are several separate listings under the subheading of "clinical trials" that feature scientific looking images that depict scientific research, such as the one featured below (see Figure 79).

Figure 79: Research. Reprinted from MD Anderson Cancer Center (2016)

Some of the images are very small and a bit difficult to discern, but, under the subheading of "Basic Science Research" there are four glass test tubes containing different liquids and, under the subheading "Institute for Cancer Care Innovation" there is a white male, wearing a white lab coat and safety goggles, standing behind a glass beaker with blue liquid in it, presumably holding it up to examine it.

Likewise, Innovations Wellness, an alternative treatment center, features a photo of a tray of test tubes next to the link on the main page about tests (see Figure 80) and a photo of an MRI machine next to the link to discounted MRI's (up to 75% off) for patients (see Figure 81).

Figure 80: Test tubes 1. Reprinted from Innovations Wellness Center (2016)

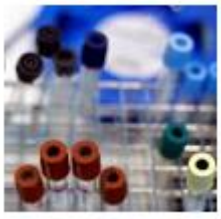
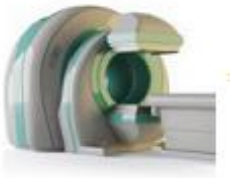


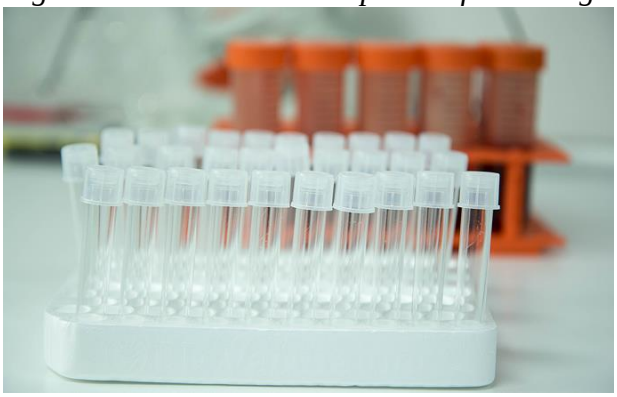
Figure 81: MRI 1. Reprinted from Innovations Wellness Center (2016)



Integrative and Functional Health Center (another alternative center) has some similar photos of test tubes and beakers (see Figure 82 and Figure 83) on the linked page to the site that takes care of all of their lab results being processed.

Figure 82: Beakers and test tubes. Reprinted from Integrative and Functional Health Center (2015)

Figure 83: Test tubes 2. Reprinted from Integrative and Function Health Center (2015)



Similarly, Innovations Wellness has an image of a microscope on the page discussing lab tests (see Figure 84).

Figure 84: Microscope. Reprinted from Innovations Wellness Center (2016)

In this way, these images portray science and research, going along with the subject matter which they represent. Often these images are inserted in parts of the site that make them logical representations of the subject matter being discussed.

Continuing with that theme, the radiology section of Texas Oncology's site features an image of what appears to be a radiology procedure, which depicts the physician, a nurse/technician and a patient (see Figure 85).

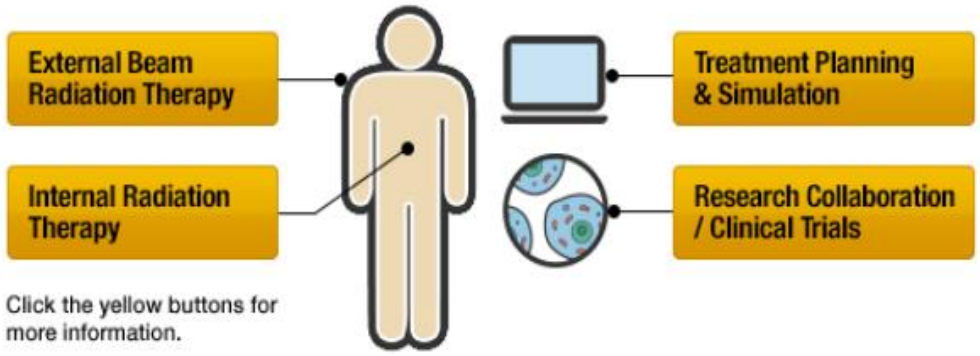
Figure 85: Radiology procedure 1. Reprinted from Texas Oncology (2016)

Similarly, the page for Radiation Therapy side effects features a scene with a technician and a patient in Radiology. However, the room in this photo is much less sterile and almost resembles a spa, with its wood floors, wooden cabinets and folded white linens (see Figure 86). The appearance of this room is a subject we will return to, later.

Figure 86: Radiology procedure 2. Reprinted from Texas Oncology (2016)

Another part of the radiation section features the same room, but the shot is from the side, and both the patient (this time female) and the technician (this time with her hair down) are smiling. Below this, there is a simple diagram (see Figure 87) that features external links that patients can utilize to get more information about each type of treatment. In this image, we see the computer (representing treatment planning and stimulation) and a magnified cell, which once again represents research and clinical trials.

Figure 87: Treatment diagram. Reprinted from Texas Oncology (2016)



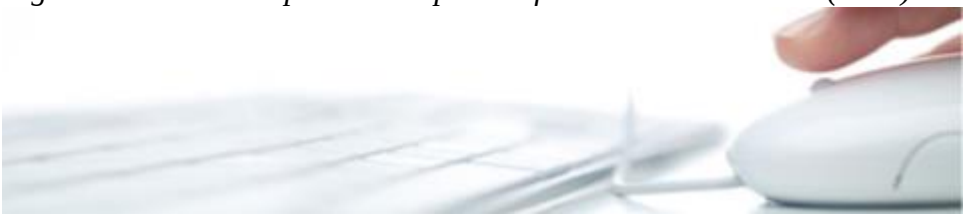
Included in the rolling banner photos for St Joseph is another image (see Figure 88) containing a computer that can be found elsewhere on their site.

Figure 88: Decision making. Reprinted from CHI St Joseph Health Center (2016)

This image of men sitting at a table with a phone and a computer is positioned under the section in the website that talks about cancer prevention and is adjacent to a paragraph about how cancer doctors and cancer experts universally agree that making good lifestyle choices are the best steps toward prevention. The implication is that this table of middle aged men is a collection of cancer doctors and cancer specialists. This photo and others like it assume that doctors and the people who are in charge of making these important decisions are male. The race of the doctors in this particular photo may, on the surface, seem intentionally diverse, but this is a photo of the actual physicians at this location. Given that the only photos of the female doctors for this same site show the physicians touching the patient that they are interacting with in a more intimate environment, the contrast of these two photos seems to reinforce gender roles. Male doctors take on the more instrumental role, taking charge and making decisions about care while female doctors take on the more expressive role, performing the actual care taking and interacting with patients. Gender aside, the inclusion of the computer in a photo intended to depict expertise and knowledge in a subject and, again, the connection to planning mentioned on another site

The image of the computer appears again in the alternative sites, Health Blossoms (see Figure 89) and on the Innovations Wellness site, with the only notable difference being that every part of the computer is white.

Figure 89: White computer 3. Reprinted from Health Blossoms (2016)



These images depicting science and technology also sometimes appear during discussions about diagnostics and advanced abilities to detect tumors at their earliest stages, as seen in this photo of an unidentified machine under a paragraph about advanced diagnostics for early detection (see Figure 90).

Figure 90: Advanced diagnostics. Reprinted from Christus Spohn Health System (2016)

Another site partners with a nonprofit organization whose goal is to eliminate breast cancer through prevention via early detection. In conjunction with this group, this

center does something called First Friday screenings, where they provide mammograms for women who are lacking financial resources. In this section of the website, there is an image of a woman with a medical professional, presumably about to have a mammogram done. The medical professional is a blonde woman wearing pink scrubs who appears to be smiling (see Figure 91). We are unable to see the patient's face, but can only imagine that, in real life, she might not match the demeanor of the medical professional in this photo. Much like some of the other images on these sites, the stock photos are of white individuals, suggesting the target audience.. However, this site is the same site that included what seemed to be an intentionally racially diverse stock photo in their careers section that was not representative of the actual employees of the hospital. Given that this hospital is in South Texas, where the majority of the population is Hispanic, this inclusion of a photo of white women stands out. It may just be an effort to appeal to a more ethnically diverse group of potential clients.

Figure 91: Mammogram. Reprinted from Christus Spohn Health System (2016)

When a traditional center has a special type of technology, that is often highlighted on the website, such as with Christus Spohn's Cyberknife technology. This technology is a noninvasive, nonsurgical method for delivering radiation therapy with

greater accuracy designed to deliver treatment with less damage to healthy tissue in fewer visits. Because it is so innovative, it has its own page devoted to it on the site, which includes qualifiers for those who might want to utilize this method, along with a photo (see Figure 92). The photo features a machine that one can only presume to be the Cyberknife technology and 2 medical professionals in white lab coats—one man with his arms folded across his chest and one woman with a hand on her hip—who look fairly pleased with themselves that might be presumed to be the individuals who operate this machinery. In this way, we can see how the innovations and technology of the site are a source of pride and a draw to the particular treatment center that they attempt to market by featuring it on the site.

Figure 92: Cyberknife technology. Reprinted from Christus Spohn Health System (2016)

While it is not an image of technology, MD Anderson takes pride in the fact that they were named the number one hospital in the country for cancer care by US News & World Report. They feature the following badge (see Figure 93) repeatedly throughout their site and devote an entire page to an explanation of the rankings. They have been ranked the nation's leading cancer hospital for 11 of the past 14 years and the institution

has been named one of the top two hospitals for cancer care in the nation every year since the survey began in 1990.

Figure 93: US News and World badge. Reprinted from MD Anderson Cancer Center (2016)

They also spend a great deal of time talking about their array of clinical trials and include a section in their site called "cutting edge research," where they talk about how one of their "greatest strengths is their ability to translate today's most promising laboratory findings into tomorrow's new, more effective and less traumatic treatments." They also say that they have "pioneered countless medical advances over the years" and generally "offer new and innovative therapies several years before they become standard in the community." In this way, they emphasize that they have something rare and unique: they have the best and newest care and they have it before everyone else does.

Integrative Functional Health Center, an alternative treatment center, makes similar claims. The site contains many articles explaining the type of testing they used and justifications for why this particular method is the best. These articles use an

abundance of technical terminology that seems designed to show their high level of scientific knowledge and expertise. They imply that they are highly scientifically advanced using the newest methods, several years before others who are considered the best in their field as stated in the following quote, directly from their site:

> "The field of oncology has become highly competitive over the past 2-3 years, due to a beginning paradigm shift, based on long standing lack of good predictable results. Mass General, Sloan Kettering, University of Texas M.D. Anderson Cancer Center in Houston, and Dana-Faber Cancer Institute of Boston have all started using and developing a similar test in the last 2 years. They estimated it may start being used in about 5-9 years. At this point, none of these centers or any others we have looked at can do (or will do) what RGCC-labs of Greece does from only ~2 tablespoon of your blood. Now that is phenomenal use of modern day technology."

In this way, they not only use a comparison to traditional methods to justify their legitimacy, but establish authority through time lines. (Integrative Functional Health Center 2016)

The Newsletter for Texas Oncology, "I CAN," itself features an MRI machine on its front cover with the words, "Power of Protons" as it's feature article (see Figure 94) and most of the listed articles on the front of the newsletter appear to discuss medical advancements. This implies that the primary focus of at least this newsletter, if not most of the newsletters, is medical advancements/technology and these things are a big part of the identity of the clinic.

Figure 94: Newsletter cover. Reprinted from Texas Oncology (2016)

Further, emphasizing this role, they note "We take our role as an innovator seriously. You deserve the most advanced care."

Christus Spohn uses a similar style of commercial, with essentially the same message: we use the best technology so that "you can stay close to what matters most," meaning once again that the technology allows people to spend less time in the hospital for treatments so that they can stay closer to home and spend more time with their loved ones and doing whatever they like. Another commonality across all sites is that they all use phrases like "cutting edge" or "leading edge technology" or "advanced care" or "innovative research" in their "about us" section of the website, which indicates the importance of these things in the identity of the site.

Overall, technology is an important representation of expertise on these websites. Sometimes, that technology is depicted in images of machines or computers, sometimes that technology is simply discussed. Newer seems to be better and seen as a particular enticement that is marketed to potential patients as a selling point for that particular site. Technology is depicted as evidence of advanced thinking and good science, which is particularly important to these sites.

Connecting to the opposite branch of medicine

While it is true that traditional treatment centers tend to use science and technology to market themselves and alternative treatment centers tend to use nature and references to the bodies "natural state" to market themselves, those are not the sole ways that each type of facility markets itself. At times, both types of centers either target the shortcomings of the opposite branch of medicine or use the marketing strategies of the opposite type of center, perhaps in order to sort of "head off" the anticipated critique of their approach and appeal to consumers who might see those differences as a shortcoming. In this way, they are able to draw attention to the weaknesses of their competition, the strengths inherent in their methods and appeal to their critics at the same time as their proponents.

Texas Oncology uses the previously discussed phrases "leading edge technology" and "innovative research" as part of the science, technology and innovation appeal to potential clients. They also emphasize the use of "evidence based care" and use this phrase multiple times throughout their website, particularly under their "why Texas Oncology" section of the website, as well as in the "My Texas Oncology Team" section, the "Executive Biographies" section, and their "vison, mission statement and core values". This sentiment was reiterated by the medical professional from that center who was interviewed. The emphasis on the particular phrase "evidence-based" seems to imply that other methods lack evidence and, in the interviews, the medical professional said as much. This idea connects traditional views of science and the scientific method. For something to have proven results, it needs to be tested and re-tested. For the

medicine to be sound, it needs to be backed up by evidence and the scientific research that produced that evidence. In this way, they emphasize science and also point out something that they perceive alternative treatment centers to be lacking, without explicitly stating as much.

Texas Oncology also says they are "forward thinking" and provide "high quality, high-touch" care. The "high-touch" aspect seems to imply that they have actual contact with patients and draws to mind an image of personal relationships and, to some extent, caring staff members. Similarly, they also mention "cutting edge, advanced treatments" (Texas Oncology 2016) and, on the same page, use the phrases "non sterile, warm environment" and "personalized care" to describe their center. These ideas of personalized care and a warm environment are often selling points for alternative treatment centers as they are seen as something a large traditional treatment center typically does not provide. According to the alternative practitioners interviewed, traditional centers and, by extension, medicine, are seen by patients as cold, impersonal and ultimately too large and concerned with the monetary and bureaucratic aspect of treatment to be able to provide a more human and individualistic approach to treatment. By using these phrases, this traditional site is also making an appeal to patients who may choose an alternative treatment center for that perceived shortcoming.

For example, Texas Oncology very much emphasizes community all throughout their website. They refer to themselves as "community based" and use it as a unique selling point for their particular site (Texas Oncology 2016) and many of their photos include images of patients and survivors in pairs or small groups, outdoors, in some sort

of garden/patio. In some photos you can even make out a pool in the background (see Figure 95).

Figure 95: Pool party. Reprinted from Texas Oncology (2016)

These images are often candid shots of interaction and really reinforce this idea of community by creating this feeling of a social environment and friendship between these individuals. There is very rarely a photograph of a person alone and this also enforces this idea of community, providing the feeling that one is "never alone" which is presumably a comforting feeling when an individual is dealing with something as devastating as cancer.

Corresponding to a "less sterile" environment, not only does the area where the patients are interacting look a bit like a resort with the landscaping, plants and pool, but so do some of the rooms depicted in some of the photos of procedures on the website. As previously mentioned, with the wood floors, wooden cabinets and folded white linens the images of rooms like that look almost like something you would encounter in a resort

or spa. The image is not only of a "less sterile environment" but, perhaps a place that is pleasant to be, as far as those things go.

Similarly, MD Anderson has quite the array of fountains and gardens. As previously mentioned, there is an entire page devoted to parks and gardens where a list and description (along with a few photos) of all of the gardens and structures in and around the hospital, along with their location. The similarity in portrayal of nature and the idea of the healing power of nature that alternative centers promote has already been discussed, but it is possible that this is also something being offered to patients as a remedy for not only the perceived shortcoming of cold, sterile environment, but also as a remedy for the perceived shortcoming of lacking a sort of "therapeutic" environment, if you will--a place where you can get away from it all to heal and become well, but also a place that almost feels like a retreat or get away. Indeed, this idea is expressed in a patient testimonial video from the Sebring Clinic, an alternative clinic that the patient describes as being "back in the trees" and "almost like a resort." The creation of structures and depiction of images that invoke those feelings by traditional centers could be seen as a way to target those patients who are drawn to that aspect of alternative medicine.

Texas Oncology also utilizes treatment that is least harmful to healthy cells and tissues (Texas Oncology 2016), which is an idea that is repeated frequently on the alternative medicine websites. At another spot on the website(Texas Oncology 2016), they say, "In the fight against cancer, we're constantly for looking more effective treatments that also minimize the side effects our patients encounter," which again

coincides with the idea of utilizing minimally invasive treatments, with fewer unpleasant side effects, that do not damage healthy tissue so that the patient gets well without undergoing any undo harm or grief in the process.

Another idea that is unique to this site is that, under information about volunteering, they also include information about legislation that could make cancer treatment more affordable and ways that people can get involved to have an impact on that. They also talk about problems regarding policies with filling prescriptions for cancer drugs and how the drugs and patient's spending and safety are compromised because of this policy. This idea is not expressed in other traditional treatment center sites and it seems a bit more in line with the ways of thinking of alternative treatment centers in that they are not happy with insurance and the idea that pharmaceutical companies are interested only in profit, rather than the health and wellness of patients.

A couple of these traditional treatment centers have specific pages dedicated to alternative medicine, whether it is offering those services at their facilities or talking about the use of them. Texas Oncology has a page which discusses the use of "complementary and alternative (CAM) therapies" to help coping with cancer. They inform patients that "CAM therapies are practiced outside conventional Western medicine principles, and they include a variety of healing philosophies and practices that are not currently accepted or used by conventional medical doctors." This site distinguishes between "complementary medicine" as a use of herbs to help with treatment already being received and "alternative medicine" as medicine that is being used in place of conventional medicine. They strongly urge patients to discuss their

options with oncologists before pursuing one of these methods and note that "CAM can introduce potential for harmful or even life threatening reactions." They warn patients that complementary medicine can interfere with the ability of chemotherapy drugs to kill cancerous cells and say that, while alternative medicine used for minor health issues is generally not dangerous, some others can be very dangerous, especially if a patient "loses the opportunity to benefit from conventional cancer treatment." They further inform patients and potential patients that their physician is "well-versed in medical solutions and CAM options" and can help them assess their condition and opportunities and determine if CAM is the right path for recovery. If so, the physician will then help connect the patient to the methods and services that are best suited to their needs. They have a reference called "Natural Standards" that they offer on their site as a link to information on CAM (see Figure 96).

Figure 96: Natural standard. Reprinted from Texas Oncology (2016)

Under this logo there is a tagline that reads, "The authority on integrative medicine." The site itself only offers the subheadings "herbs," "conditions," and "interactions" and reads more like a database or glossary than an educational source. Under the link, Texas Oncology also has a disclaimer that reads, "Please note that the

information available through this link is not provided by Texas Oncology, and Texas Oncology does not necessarily endorse this information. All information provided through this link is for your reference only and does not constitute medical advice. Please consult your physician before acting or relying upon such information." While the disclaimer is certainly for legal protection, it also seems to create an idea that these alternative medicine options are not necessarily safe or good—certainly not as good as traditional medicine.

MD Anderson not only has a page, but an entire section of their website dedicated to Alternative medicine because they have an Integrative Medicine Program at their facility. (MD Anderson Cancer Center 2016) "The Integrative Medicine Program engages patients and their families to become active participants in improving their physical, psycho-spiritual and social health. The ultimate goals are to optimize health, quality of life and clinical outcomes through personalized evidence-based clinical care, exceptional research and education." They provide "access to multiple data bases of authoritative, up to date reviews on the evidence and safety for the use of herbs, supplements, vitamins, and minerals, as well as other complementary medicine modalities." Though they refer to their program as "integrative" it seems to correspond to Texas Oncology's ideal of "complementary" medicine. Similar to Texas Oncology, they provide access to resources that inform them about the nontraditional options and place an emphasis on "evidence-based" care and using these options within the confines of traditional medicine's standards and what they believe to be safest and best.

The program has a research department which "focuses on reducing the negative consequences of cancer diagnosis and treatment through studying the use of modalities such as acupuncture, meditation and yoga to treat side effects and improve quality of life." They also study the use of plants and other natural compounds to treat cancer and cancer-related symptoms and the benefits of physical activity, nutrition, stress management and social support on health outcomes. The program has an education component whose goal is to "provide authoritative, evidence-based information for health care professionals, caregivers and patients who would like to safely incorporate complementary medicine therapies with conventional cancer care." To aid in patient education on what they refer to as "complementary and integrative medicine", they have an online audio and video library which includes talks about different therapies, meditation sessions and music therapy sessions. Through the description of their educational goal and services, along with their research program focus, they explicitly refer to alternative medicine as complementary medicine and, again, refer to it under the same terms as Texas Oncology: they aim to treat side effects, improve quality of life and safely incorporate the appropriate methods into conventional treatment. They go on to say "The Center provides services and programs that work together with conventional cancer care and focus on physical, mind-spirit, and social health," further articulating this notion of complementary medicine and the avenues they utilize in their program. Unlike Texas Onoclogy, MD Anderson not only provides access to databases, but also offers educational activities and trainings. The topics visible for upcoming activities place an emphasis on prevention and talk about how lifestyle changes could help prevent

cancer (MD Anderson Cancer Center 2016). They also publish a newsletter and hold classes for patients, caregivers and the public, which cover topics like "gardening, cooking, meditation, yoga and art," which they say will help everyone live more healthy and balanced lives. The following photos of an older couple jogging or hiking in a park full of green trees (see Figure 97) and a yoga class in session (see Figure 98) accompany this idea to illustrate the kinds of classes they offer.

Figure 97: Couple in park. Reprinted from MD Anderson Cancer Center (2016).

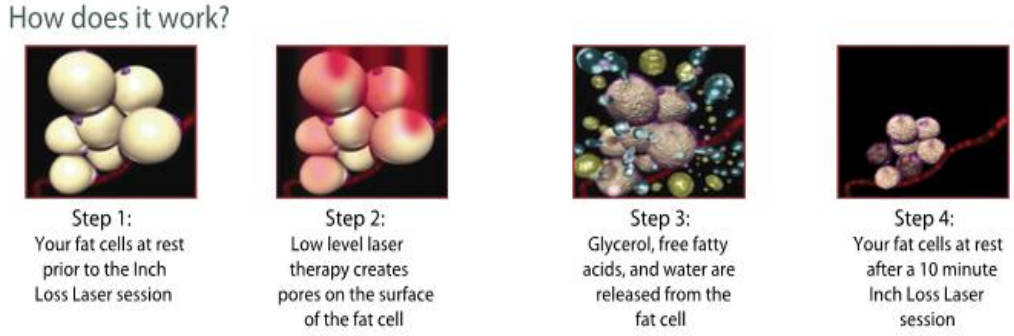
Figure 98: Yoga. Reprinted from MD Anderson Cancer Center (2016)

Under the "why support us" section of the Integrative Medicine Program section, they state that "about one third of cancer cases could be prevented through lifestyle changes such as diet, activity and weight management." Further, "cancer is one of the biggest challenges a person can face. Worries about the future and the physical toll of care can cause patients to suffer both physically and emotionally. Integrative Medicine Center is here to help." The page then discusses how the center offers therapies that reduce patients' stress and anxiety and improve their physical, mental and emotional well-being, finishing with the statement, "In consultation with your primary care center team, we will design a comprehensive approach to your cancer care." The implication is that stress reduction and a healthy lifestyle are a large part of what they define as alternative treatment. While that is a component of what alternative treatment centers

talk about, it is not actually their treatment method. Generally, these things are held up as an ideal way to live one's life if one wishes to be healthy and, while the idea exists that remedying anything that is out of alignment with those ideas can certainly be helpful, it is not necessarily promoted by alternative centers as a type of treatment itself, but is rather part of total wellness.

Traditional treatment centers are not the only ones who utilize ideals, phrases and images typically found in the opposite branch of medicine. Alternative centers do this too, particularly in their utilization of words and images representative of science. Previously, I showed that they used these images in their phrasing, depictions of computers and images like the double helix and test tubes as they represent genetics and research. They also utilize images that appear more technological or scientific when discussing the types of treatments they use that are unique to their particular clinics. Typically, rather than show the actual procedure, itself, they use these images to demonstrate that the particular method is actually sound. For instance, Energy Health Systems uses images of cells before and after their Inch Loss Laser session (see Figure 99) as evidence of the science behind the procedure and it's merit. (Energy Health Centre 2016)

Figure 99: Cells before and after. Reprinted from Energy Health Centre (2016)



Similarly, they use the same sort of language and images rooted in science and technology that traditional centers would to talk about their breast health screening procedures, breast thermography (see Figure 100) and the Halo Breast Pap Test (see Figure 101). (Energy Health Centre 2016)

Figure 100: Breast thermography. Reprinted from Energy Health Centre (2016)

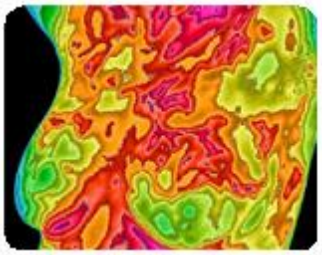
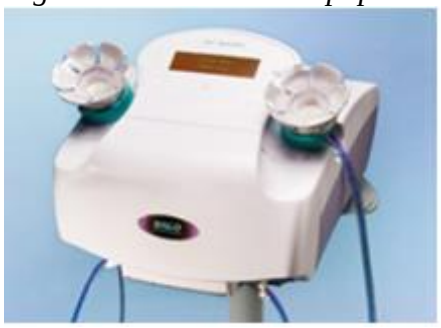


Figure 101: Halo breast pap test. Reprinted from Energy Health Centre (2016)



When these centers use these images and ideas in this way, it seems to be as a counter to "unscientific" claim or that they lack the "evidence-based" medicine that traditional centers tout. In this way, they answer those critiques.

Alternative medicine sites mention that CAM has withstood the test of time and comes from what is sometimes referred to as "ancient eastern medicine" (Nature Blossoms 2016). To ward off claims that their methods are antiquated, the traditional treatment centers often use the phrase "cutting edge" technology and some alternative treatment centers use the same phrase, too, as is seen on the home page of Innovations Wellness Center. "Dr. Wilson teaches patients to use diet, exercise, and make life style changes with traditional and cutting edge natural options to enhance their bodies' ability to ward off and combat disease." However, in this instance, the phrase cutting edge is used to describe natural options, rather than technology. So here when can see an appeal to the idea that alternative medicine also has "cutting edge" or updated, more innovative methods for their type of medicine as well. Again, this clinic responds to a critique against their type of medicine by addressing it on their site and therefore attempt to appeal to their proponents as well as their opponents.

Similarly, Integrative Functional Health Center defines their method of treatment and their philosophy on the type of treatment they utilize in the following paragraph: "Some people call it alternative medicine, but we see it differently. We recognize the value of integrating functional diagnostic testing, natural medicines, supportive cancer care, detoxification, nutrition, with additional therapies to offer "The Best of Both Worlds" in this new millennium of health care (alternative first then traditional only

when needed)." (Integrative Functional Health Center 2016) This paragraph is particularly interesting. It redefines what innovation means by moving the focus away from traditional medicine and that sort of science to utilizing alternative first and only using traditional when it is needed and calling this the "new millennium of health care." This is what this clinic sees as the wave of the future. Additionally, they also start to hint at some possible problems with traditional medicine (or at least establish that there is potentially a downside to that method and likely theirs, as well) by saying that alternative medicine should be used first, rather than traditional, and also in using the phrase "best of both worlds." They go on to say, "We combine old fashioned doctor patient care with 21st century technology," which again implies that modern equals technology and, perhaps, is "the best of" the traditional world. This also implies that "old fashioned doctor patient care" is "the best of" the alternative world. By appealing to both their weakness and their strength at the same time, they make it known that they offer solutions to both, ultimately making them the superior choice and, just like the traditional centers, allowing themselves to appeal to both critics and proponents.

This idea of "old fashioned doctor patient care" being absent is a common critique of the traditional treatment centers and, much like the traditional centers utilize the critique of alternative medicine lacking science, research or evidence to back it, alternative treatment centers utilize this idea that traditional centers are cold and impersonal. They often do this through a site wide emphasis on personalized medicine and "personalized patient centered care" as seen throughout the site for Integrated Functional Health Center.

The Burzynski Clinic is a little more direct in the way they address this idea. Under their "Our Approach to Cancer" section on the website, they state that they believe "that every patient requires a unique treatment plan" and that they "do not believe in "one size fits all" treatments for cancer patients.

> "Our care encompasses a personalized and customized approach. Our goal is to be as sophisticated as possible when treating our cancer patients. This means minimizing the use of potentially ineffective medication."

They first point out the idea that, while others may believe in "one size fits all treatment plans," they do not. In this way, the Burzynski Clinic directly states their grievance with traditional medicine and the way that they address those issues, which makes them the superior choice.

A second issue--the use of ineffective medication also differentiates alternative from traditional. The same clinic's mission statement reads:

> "For over 35 years, Dr. Burzynski's cancer research and care has been inspired by the philosophy of the physician, Hippocrates, to 'First, do no harm.' True to this philosophy, our approach to treatments are based on the natural biochemical defense system of our body, capable of combating cancer with minimal impact on healthy cells."

Elsewhere, they say that they utilize a "customized combination therapies consisting of conventional and other therapies to maximizeeffectiveness while minimizing the impact of traditional therapies." Burzynski focuses on this idea that more natural medicine, or at least medicine that falls in line with the natural state of the body, is better than those typically offered by traditional treatment centers. If medicine is harmful or ineffective, in particular, it is not something the clinic would endorse.

Getting at this idea of the natural state being best, Lane Sebring of the Sebring Clinic discusses the type of medicine utilized in the clinic, in a video on the clinic's website saying, "It's orthomolecular medicine, we use the body's own chemistry. We de-emphasize medication. In fact, a lot of our goal is to get people off their current medications and show them how to live a life in a lifestyle that prevents and connects to reverse disease." On the website for the center, they also state "Our unique healthcare professionals can "think outside the box," and provide extraordinary service to fulfill your health and nutrition care needs," placing emphasis on constantly researching cutting edge scientific data and products designed to intervene at the cellular level to correct imbalances which cause or perpetuate disease conditions. In this way, to be natural is also to be innovative and to be more informed than to simply prescribe a medicine for a symptom. These two clinics endorse the ideas that natural is better, meaning, avoiding medication, and bring to light this idea that medication (especially cancer treatment medication) can potentially cause harm while fixing the ailments of the body. Once again, we see one branch addressing the perceived shortcomings of another and how they address these issues to show their superiority.

Doctor presentation

All of these treatment centers, traditional and alternative alike, list biographies and photos for their physicians. Some traditional centers like St Joseph's feature these types of backgrounds for not only their physicians, but also their technicians, patient navigators and social workers. Other traditional centers like Texas Oncology only feature biographies of the board members or, in the case of MD Anderson, only feature

them for the President of the center and the International Patient Center. As previously mentioned, the bios for alternative treatment centers tend to contain more personal information, including their family lives, how they got into this branch of medicine and their philosophies—one was even written in first person, rather than third.

The photos that accompany these biographies also vary—at times, physicians may appear in a collared shirt or suit and tie or a white lab coat, with or without a stethoscope, or they may appear in more brightly colored business casual type clothing. One thing that does not vary is that none of traditional physicians are pictured wearing the more casual or brightly colored clothing. Below are four such photos: the first two are traditional treatment center physicians and the second two are alternative treatment center physicians.

The 2 traditional treatment center photos are from Texas Oncology (see Figure 102) and St. Joseph's (see Figure 103), respectively.

Figure 102: Traditional bio photo 1. Reprinted from Texas Oncology (2016)

Figure 103: Traditional bio photo 2. Reprinted from CHI St Joseph Health Center (2016)

The 2 alternative treatment center photos are from the Sebring Clinic (see Figure 104) and Energy Health Centre (see Figure 105).

Figure 104: Alternative bio photo 1. Reprinted from Sebring Clinic (2016)

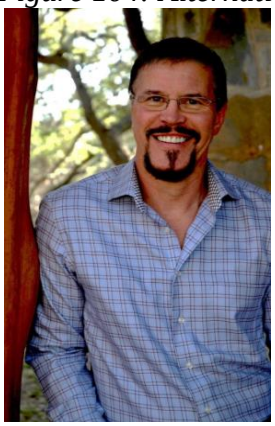


Figure 105: Alternative bio photo 2. Reprinted from Energy Health Centre (2016)

While there are alternative physicians whose appearance are similar to that of traditional physicians in their photos, as with the case of Integrative Functional Health Center (see Figure 106) and Innovations Wellness Center (see Figure 107), below, there are no traditional physicians whose appearance resembles that of the previously shown alternative physicians.

Figure 106: Alternative bio photo 3. Reprinted from Integrative and Functional Health Center (2015)

Figure 107: Alternative bio photo 4. Reprinted from Innovations Wellness Center (2016)

There is also a noticeable difference in the proportion of female lead physicians at alternative treatment centers. As opposed to traditional treatment centers, where lead physicians are more often male than female, the lead physicians at alternative treatment centers are more frequently female than male.

As far as the written portion of these biographies, one thing that all of them have in common is their emphasis on their credentials, particularly with respect to their education and licensing, professional organizations and professional experience and achievements. There is a heavy emphasis on education and certification. Both alternative and traditional physicians list their degrees and where they got them from, along with where they interned in internal medicine. Though the type of degrees and certifications are different, they all signify expertise in their fields, whether they are in chiropractic medicine or radiology. They also all discuss the physician's awards and fellowships and even their graduating ranks, along with their career relevant experience

and organizations they are affiliated with. These titles, certifications, career experiences, awards, and affiliations legitimize the claims of the physicians and act as a sort of capital that practitioners can use to demonstrate proof of their expertise.

Licensing and accreditation

Still, alternative treatment centers do seem to go to extra lengths to demonstrate their expertise. At times, this is through the use of images of science and other previously mentioned techniques for appealing to those who prefer traditional medicine. Alternative medicine may also go through the process of obtaining FDA approval, as the Burzynski Clinic has or, as Health Blossoms has done, they may explain their training and licensing.

According to Health Blossoms, "Naturopathic doctors are trained at accredited, 4-year, residential naturopathic medical colleges and pass a postdoctoral board examination (NPLEX) to become licensed." The training includes conventional medical sciences and natural therapeutics.

There is a sense that they are not only educating readers about the process in a type of medicine where the educational process and requirements are not as well known, but also qualifying their type of medical degree and expertise as legitimate.

Health Blossoms also educates readers on the licensing policies for the United States. Seventeen states, the District of Columbia and the territories of Puerto Rico and the Virgin Islands, have licensing and regulation laws for naturopathic doctors. "In these states, naturopathic doctors are considered primary care providers and their scope of

practice varies depending on the state. Licensed naturopathic doctors must complete continuing education requirements to maintain their license."

By educating readers and potential patients on the licensing requirements and laws, this site also provides proof that there are standards of excellence which naturopathic doctors must meet in order to be licensed and treat patients. Again, this qualifies the practitioner's expertise and abilities as someone who can be trusted with a patient's health and well-being.

CHAPTER V

INTERVIEW ANALYSIS

6 traditional medical professionals and 4 alternative practitioners were interviewed. Of those, 4 were male and 6 were female. Interviews were confidential, and as such, each respondent was assigned a combination of a number and a letter as an identifier. The letter A indicates that the respondent practices alternative medicine and T indicates that they practice traditional medicine. Numbers were simply assigned by the order they were interviewed in. Across all the interviews at both types of facilities, several themes were recurring: polarization between the two branches of medicine, differences in the role practitioners played in patient care, a perception that patient trust in physician directives had changed over time, mixed feelings about the impact of widely available health information over the internet, and a consensus that insurance had more of a constraining effect on care seeking than an enabling effect.

Polarization

A certain amount of polarization between the two branches of medicine was evident throughout the interviews. Both alternative physicians and traditional physicians were quick to point out the flaws they perceived the other branch as having. Alternative practitioners often referred to traditional medicine as "a fast food model of health care" and "factory-ish."

Respondent A2 stated:

> "I feel like, the whole 360 degree perspective is the true way to give patient care, not just a 5 minute, 7 minute visit, which is how, this is what medicine is becoming in a lot of places, which is not what it used to be years ago, but

> unfortunately with doctors now being called providers and such and it's kind of a fast food model of care and that shouldn't be the case."

Similarly, respondent A4, a practitioner who had previously worked onsite with a traditional physician said:

> "The doctor I worked with most recently, I mean, he's seeing patients every 15 minutes and can barely recall a name or a conversation without charting it immediately after the 15 minutes has passed. And so, I think patients feel that. I feel like it's factory-ish and, I think people are less trustworthy because of insurance. Maybe the doctors don't feel like they have much control anymore because it's what insurance is allowing them to do. Or maybe that amount of time isn't enough."

These ideas of seeing patients as part of a very quick, standardized process lend to the idea that there is a lack of personal care and, by extension, personalized treatment. According to alternative practitioner A2:

> "If you're in a big institution, you have to ask all these other people, you have to ask your supervisors and follow protocol and that's what's happening with medicine, now--you just have all these practices in these institutions and hospitals and you have less freedom in medicine, so you're getting a very cookie cutter treatment plan for the most part and that's, so, that's what this (his clinic) is great for. Getting the art of medicine, personalized care that's, I think, that's really hard to replicate because I've been to big local hospital and it's a cold model, for employees and patients, I feel. So, I think definitely there's more heart in the small places and you can tell. You can empathize more. You don't have to ask permission to do some of these things."

These ideas expressed by the practitioners interviewed reflect the ideas on some of the Alternative treatment center websites about how traditional treatment centers provide "one size fits all treatment," which is remedied by alternative medicine's highly personalized approach and treatment plans. Alternative practitioner A2 stated that he felt some people preferred alternative medicine because:

> "Um, cause it gives more than what you usually get at that cold doctor's office. There's just a lot more caring and they're seeking to have better outcomes at the

> end of the day, right? I mean, in this setting of Cancer, a lot of cancers are pretty dismal, right? So, if you can extend lives, for somebody, doing something different, giving them a better quality of life, that's why they come here, right?"

With this statement, he reveals that he feels that traditional medicine is a cold model that lacks a sense of care and compassion and that he feels this is something alternative medicine can provide. Indeed, traditional physicians are aware of this flaw and do acknowledge it in their interviews. A few nurses mentioned wishing they could do more for patients or that they had more time to devote just to them instead of all of the other tasks they had, such as an oncology nurse at one traditional treatment center who stated, "I sometimes wish that we had more time or more compassion." She went on to say the following regarding patient dissatisfaction:

> "Um, people who are unhappy with care kind of fall into 3 categories for me. 1 is outpatients who are upset with how long it takes to get into the hospital, which is true, it's awful—its' ridiculous, they have to sit downstairs and get checked and instead of having a dedicated outpatient clinic with outpatient nurses, we have in-patients who are acutely ill and need their attention and then they are going over and also, oh here's an outpatient who needs a transfusion, so they end up waiting longer. Um, our blood bank, they try to do outpatient stuff quickly, but they have people who are hemorrhaging in the OR that they have to take care of. So, it would be a lot better if we had a dedicated outpatient area, which is something people are supposed to be working on, but haven't been. People are dissatisfied with how long it takes. I mean, it shouldn't take that long and they're right. People are putting their lives on hold for a whole day and I get that."

T7 highlights one of the big reasons for dissatisfaction with traditional medicine: excessively long wait times to receive care, in particular, those who need to be admitted to the hospital to receive treatment. Because there are other people with more life threatening health issues and there is not a dedicated area with dedicated staff to treat those who are in a non-crisis situation, admission to the hospital for treatment can take a

very long time. In addition, the accommodations for those who are in for treatment are not terribly nice.

> "There are people who are dissatisfied with how it's not like a hotel, you know what I mean? They're there for a long time and I get it, but you know, the budget goes toward medical care instead of a more comfortable bed or walls and you're stuck there, you have no control over anything and it's awful and I'm sorry. I'm sorry. It's an old hospital and we're working on it."

Resources do not go toward making beds and rooms more comfortable, but rather toward the delivery of care. So, even though the patients may be there for a very long time, there isn't much that can be done to make patient the patient's stay a nicer one, in terms of the appearance and feel of the facilities. This can be very frustrating for patients, just as a lack of time for patients once they have been admitted can be.

> "And then there are people who are just, sometimes we don't have the time. The time we really need to and that's a fair, reasonable complaint. There are days, there are frequently days we don't have time to eat lunch and that's not our patient's problem, you know? I mean, that's not. They're here to get medical care and emotional care and I feel terrible when someone is crying and my phone rings 5 times because everybody else needs something too. It's really something where we kind of have to be present with our patients and it's sometimes easy to forget that because we get so busy and so that, that happens and I get it. They deserve more time, we just don't have it."

Here T7 expresses her frustration with the lack of time available to give patients, along with the legitimacy of their complaints. The source of this deficiency is not a conscious effort or one that she wants to continue. Rather, it is a structural issue and part of a system that makes the resources available for her, as a nurse, to give patients inadequate. Similarly, T6, a patient navigator acknowledges this problem with time and ability to give it to her patients based on conflicting duties.

> "A lot of my stuff I do is really important on a lot of different levels. I mean, you're in research, you know. But that pulls me away a lot of times from patient

> interaction and I wish that didn't happen and that was an easier thing, but like, you're pulled between one and the other."

While acknowledging that the process has created this strain, she also indicates that, this recognition of a flaw with the system that makes it less geared toward personal care for patients has led to changes intended to rectify it.

> "…we're constantly changing. Uh, what I did 4 months ago is different from what I'm doing now, I mean every 5 or 6 months the whole program really kinda changes based on our data telling us that we need to do something different here, versus here and it's all, it's all about the patient experience. We say that at almost every meeting. "Well, what is the patient experience? What can we do to make this better for the patient?" and um, I think as long as we keep doing that and that it's about the patient—we're not treating a breast cancer, we're not treating a colon cancer, we're treating a patient, we're treating a person that has all kinds of problems and how can we improve their health. Doesn't matter if it's cancer or what it is come to *hospital name* and it's about how we're gonna improve your health and how we're gonna make life better for you and help you. Yeah, I think it's just that constant evolution of addressing needs"

Just as alternative practitioners had unfavorable judgments of traditional medicine, traditional physicians had unfavorable opinions about alternative medicine. They often felt that alternative medicine was not backed by science, or, as they put it, "evidence-based." This phrase was repeated not only in interviews, but on traditional treatment center websites, particularly the treatment center where T1, an oncology nurse, was employed. When asked why she felt patients' preferred traditional medicine, she said:

> "I think they want to go somewhere where they have the best chance of not only survival, but also of getting kind of evidence based care."

When asked what she meant, she said:

> "Um, I feel very strongly that I'm not gonna recommend anything that doesn't have research behind it and part of that is having worked in research. I feel very strongly. You know, people can kinda throw ideas out and if they're not research

> proven, then no. And I'm all about the natural stuff, like as far as, but once you have a life threatening disease, you don't get to like gamble with that."

In this way, she clarifies that, for her, evidence based means that research has proven that these methods are effective. While she thinks that natural things are good, anything other than a research proven method is a risk and not one that is worth taking when a person's life is at stake. Other physicians echoed this sentiment regarding research proven methods. T4, an oncologist at a very large research driven treatment center, said:

> "today, you know, places like *hospital* we do these clinical trials and we look at these outcomes and so, when we make a recommendation, we try to make that on evidence based medicine. This is the most effective treatment, you know, 100 patients underwent this treatment, the majority got better."

Scientific studies and statistics were the most valuable measure of the effectiveness of a treatment method according to traditional practitioners. T5, a radiologist at another hospital said she felt patients' preferred traditional treatment for the following reasons:

> "Probably because it's been around for awhile, there's been more research. Um, we have statistics on radiation because you know, radiation has been around for years. And there's more studies with the results of radiation. You know, we've seen patients 5, 10, 15 years later to not have any cancer and sometimes the nontraditional can seem a little experimental rather than having how it actually works, you know, how the radiation works. All I can say is we've seen the results of radiation. We have the statistics. We've seen years and years of patients that have the radiation and we've seen how it treats the cancer, how it breaks down the cells so we know how it works and, the results are different for every patient, but in the grand scheme of things, it's been around for awhile and I know how it works. I can't say the same for the nontraditional methods. I've not experienced a lot of patients that have tried it. And so, just because we have a proven record, I would say it works, but I can't you know, disregard nontraditional methods because I don't know a lot about it and I don't know a lot of patients that have tried it."

T5 again emphasizes the value of proof in repeated outcomes and numbers and even says that alternative medicine seems a bit experimental. However, she does say that since she doesn't know much about alternative medicine, she cannot disregard it entirely, a subject we will return to, later. Other physicians, like T6, a Nurse Practitioner at a traditional treatment facility felt that not only proof through research, but also standardization of the supplements or other items that are utilized would be valuable.

> "I think it would be nice if alternative treatment had better ways to prove that they were more effective and standardized. Like, I'm talking about um, herbal and vitamins and stuff. I mean, just recently there was this study, I don't remember who it was but they took the vitamins off the shelf at Walmart and Target and somewhere else and they didn't even have 1% of what was in the labeled bottle and, I think, if we got a better standard measurement system of what we are taking—cause we do know certain phytonutrients and so on makes a difference. What you eat and put in your body makes a difference to your cancer risk and tolerance of cancer treatment and recurrence and all of that. We know that has an effect, but, the average person out there who's taking herbal and home remedies, it's hard to find good sources because there's no standardization of "I'm buying this, I'm getting this" and then you compare this study to that study and you see well they used this and it didn't have you know, so that's the challenge for me. It's just, what's truly effective?"

She feels that while nutrition is very important and can be helpful, it is very difficult to decipher what exactly patients are getting when they utilize these supplements and herbs.

> "I, you know, I like to know that what I do is study supported, evidence based and, it's gonna be effective. you know you see too many stories where people go somewhere and get some kind of concoction and who knows what it is and their health is greatly diminished because of it and then they're back here with us again at some point and they're trying to improve what you can and then there's that regret."

She also indicates in this statement and the following that, not only can this lack of standardization be harmful to a patient, but it may, in fact, be some sort of scam:

> "there's too many things out there that, their incentive for telling you that this is the best thing in the world isn't because 'I wanna make you better', it's because'

> I wanna make my pocketbook better' and I think a lot of people get caught in that."

While she does have these feelings of distrust and concern for patients, she mentions she believes there are benefits to alternative methods, even if they are not measurable by scientific methods or able to be quantified.

> "Um, I think, there are some things that have been detrimental to patients because they've been sold on, "well, this will help you" and they put all their faith in it and it's something that hurts them. I worry about that, um, but as far as the reiki—I always say that one wrong—area and some of those, as far as, if they're not depleting the patients money, who they are already limited on their means, I think there's a benefit to it. Now, how do you measure those benefits? I don't know. But I think there are."

As evidenced in these quotes, there is a certain level of polarization between these two branches of medicine. This polarization appears to stem from hearsay—whether from previous patients or others—and personal experience. However, interviews revealed that actual knowledge of alternative medicine was limited. Often, the biomedical professionals didn't know what alternative methods were and referred back to the resources that their particular facility provided. For example, in response to a question asking her how knowledgeable she felt about alternative medicine, T1 stated:

> "Um, for actually just straight up treating cancer, I don't . I know I'm not knowledgeable about any other treatment than what we have. I feel like, as far as treating side effects, um, you know, I can sort of offer suggestions for some alternative things um, and certainly people come to us all the time with "hey, I want try this supplement or this thing" and we actually have a great database that we can say, "lets make sure this is safe." Again, I don't really have any data that says this is gonna work, but we can try it, that's totally cool as long as it's safe."

Similarly, T4 answered:

> "Personally, probably not very much. But as you're asking me, we do have a department of alternative medicine here at *hospital* and they are exploring, they have these seminars on all types of alternative medicines and you know,

> things like acupuncture for chemotherapy and you know, nausea and pain, you know we did, we do have acupuncture here as well as many other types of alternative medicines that are explored."

These two physicians admit to not having much knowledge of alternative medicine and are quite dismissive of this method that they know very little about. However, they are very confident in the ability of their respective hospital's resources to fully supply adequate answers in place of the ones they don't have. The purpose of these resources appears to be to provide information to patients on which of these methods the traditional treatment centers approve and to provide certain types of alternative treatment that they approve as a complementary service, rather than an alternative treatment. T4 mentions acupuncture, but T6, mentions different alternative treatments:

> "Uh, well, we employ or include yoga, tai chi, massage and, we're even utilizing the uh, um, vaporizers of the essential oils over at the cancer center. So, we do employ those methods, um to help with some symptom control and just stress relief. So we do offer that kind of thing. Uh, and I think that, along with the clinical and traditional medical field, I think that blending works really well and um, they also have a registered dietician that can work with them on good nutritional, you know the whether it's supplements, whether it's eating right, most of our patients tend to gain weight, so getting to a normal BMI, so to look at all those parts and address it and again, that spirituality is just as important as—they're having a faith crisis. Like "I sinned, God's caused my cancer." You gotta work with a patient. That's very destructive for them, so you gotta reel em back in based on whatever their belief system in and address those issues for that patient"

This patient navigator seems to view anything that isn't the actual treatment of the cancer (such as chemotherapy, radiation or surgery) as alternative medicine. This includes things that most people would not define as alternative medicine, such as elements of a healthy lifestyle like diet and exercise (tai chi and yoga) or things like essential oils. However, she does acknowledge that this is for symptom control.

Interestingly, she drives home the idea that the patient's belief system is very important and treats that as an element of alternative medicine as well. This may be because her hospital is religiously affiliated, thus she sees more patients with strong religious beliefs that she must work with.

In stark contrast to T6 who mentioned things that might not even be considered alternative medicine by most people, there were those physicians who, while they acknowledged their knowledge of alternative medicine was limited, only noted the most extreme examples. Oncology nurse T7 said:

> "um, when it comes to herbal supplements and stuff like that, I don't know too much about it. I know I've had patients who think that they have cancer because they have an acid base imbalance in their body and if they take a lot of baking soda it will cure their cancer and I have to explain to them that that's what your kidneys do, so your kidney, like your body is 7.4, that's your PH. Your kidneys and your lungs do the respiratory and the metabolic acidosis. That's how your body regulates itself and keeps it at a specific PH so all you're gonna do is throw yourself into an imbalance. Um. And, uh, that's just not how science works (laughs). Stuff like that, I've seen some of that because a lot of (inaudible) completely cure your cancer. But that is not how that has worked in my experience. Um, so and we have patients who are from Mexico who want to try and drink silver. Things like that. Yeah, it's a big a big thing to drink um I can't remember what it it's called but um, yeah it's like a silver solution that you drink and it forms little deposits of metal in your body. Not a great thing. It's a big thing around Mexico."

The physician dismisses alternative medicine and indicates that, to believe in alternative medicine practiced and accepted based on ignorance.— She provides extreme examples of alternative medicine to demonstrate her use of science..

Just as the traditional practitioners were aware of the common critique among alternative practitioners of their branch of medicine being cold and impersonal, the alternative practitioners showed some awareness of these extreme examples and

interpretations of exactly what alternative medicine did. An alternative physician from one treatment center demonstrated this:

> "We don't just give care like at the x clinic—I just bring that up because it's a fairly well known clinic where they just give people smoothies and enemas and stuff like that—we don't do that here. Um, you can, you can do that and focus on nutrition. I think nutrition is huge, but we need to focus on other things, so that's our focus."

A2 references another extreme example what the perception of alternative medicine is, based on the methods of a clinic in another country. He feels that all alternative medicine is lumped into that category and tries to dispel this myth by bringing attention to the fact that, while nutrition is important, it is not the only focus and certainly not the primary focus of the clinic in which he practices medicine.

The alternative practitioners were often also MDs, so they were familiar with the other branch of medicine and could articulate why they had chosen their branch of medicine as it related to their knowledge of traditional medicine. In response to the same question that was asked of traditional physicians—"how knowledgeable do you feel you are about the opposite branch of medicine"—A2 replied:

> "I'm very knowledgeable. I was trained in internal medicine, so I know all the—I'm board certified in internal medicine. I've studied oncology, I do have an oncologist here and I know all the guidelines and I wanna do that and some more. I'm very knowledgeable in my area, but you always have to keep up to date with the latest training."

This particular practitioner had a parent who was also both an MD and an alternative practitioner. Another practitioner was very knowledgeable about traditional medicine because she came from a family of people in science based professions with a mother who was a nurse and brother who was a professor of biology and had originally started

out in the pharmaceutical industry. She became interested in alternative medicine after an injury, but then took an even greater interest in alternative medicine for cancer, specifically, when her husband was diagnosed with cancer. Similarly, A1, an alternative practitioner who runs his own treatment center, came from a medical background, originally. He practiced medicine for years and got tired of running out of answers for patients and endlessly writing prescriptions for symptoms instead of addressing the cause of the symptoms, so he entered the study of alternative medicine through nutrition.

> "I really enjoyed that type of thinking and that way, but, after awhile it became so routine, I became bored with it and, uh, it wasn't interesting enough for me. And, um, also, um, I realized that here I was prescribing Prozac or any other prescription medication and patients would ask, 'well how long can I take this? how long can I take it?' and I would say, 'well, I dunno…and neither does anybody else."

For all of traditional medicines claims that they will only utilize "evidence based care," A1 brings up an interesting point regarding the knowns and unknowns about traditional medicine. While there may be a great deal of research on the outcomes of utilizing particular drugs and treatments, there is not a great deal of evidence about how long an individual has to take a particular prescription or even how long it is safe. In this way, there is not as much certainty to every aspect of traditional treatment—from beginning to end—as its proponents would argue. A1 continued:

> "And I was very uncomfortable with that and so, then I had a patient that came in and gave me a list of problems that they had, quite lengthy and then they had, they ended that list with, 'but I don't wanna take any medications.' So, I think I was really tired that day and it was the end of the week, not much sleep and I said, 'so what did you come to me for? I'm a doctor of medicine.' And that echoed in my ears immediately and it didn't sound good. And uh, the patient allowed me to back up, which I did, and came up with a pretty natural treatment for all of his stuff and I followed up on that and it seemed to work well."

Here, A1 brings up a problematic aspect of what it truly means to define one's self as a "doctor of medicine:" the notion that the most important aspect of being a doctor is prescribing medications. The presentation of this patient's medical concerns was problematic because they wanted a solution without medicine, something that, as a traditional physician, he didn't feel prepared to do. After this incident, he decided to go to a nutrition conference and experienced a change in his way of thinking as one of the only MD's in attendance.

> "You know, I decided I was gonna stick it out cause I was gonna know both. OK, that's how I justified this. They were only gonna know one, but, so, so, they were treating upstream at a causal level and medicine virtually never investigates or even questions cause, so I had a drug for every symptom. So after attending these conferences and beginning to broaden my thinking and recognizing that between different causes, I can get rid of 3 or 4 medications and it usually doesn't need a drug to treat and, even strangely, you can correct it and they don't even need to take it anymore, which is uh, the upstream treatment, supplementation, sort of rebalancing their normal biology to working like it's supposed to. Actually, it can have a permanent effect, barring any further insults…and so, that paradigm, that whole mentality, that whole mindset of thinking doesn't exist in medicine and the reason is, because we keep treating the symptoms. So, this was very empowering—for my thinking, for my patients, etc."

This shift in thinking allowed A1 to treat the cause of the symptoms, rather than just prescribing medications for each symptom, something that was beneficial to both himself, and his patients. Again, he points out a interesting issue with traditional medicine—the idea that physicians don't actually look at healthy people as a basis for how to make people healthy, but rather that they only look at those who are ill:

> "Now I have a template. Medicine has no template. They don't even bother to look at health. Our lab values basically come from averaging a bunch of sick people, knocking off 5% at each end and that's where we get our ranges. What we should be doing is looking at very healthy people and finding out what it should be and that should be our goal. Then we should be able to judge things so

> that we can get 'em in that range, listening to the patients to find out what's working for them. But, optimizing is neither, never a part of medicine. So, it's a concept and, if you think about it, concepts don't exist in medicine. There aren't concepts. It's all data accumulation, you know?"

A1 notes that this devotion to statistics and science not only ignores the healthy to focus on the sick, but also ignores an overarching way of thinking about health and medicine. Rather than only being concerned with the quantitative aspects of "evidence based medicine" (success rates, failures, percentages, etc), he feels that traditional medicine ignores the why behind illness, health, and treatment. While he did discuss reasons he was not fond of traditional medicine, this practitioner still acknowledged that some things were better treated with traditional medicine.

> "Well, I, to be honest with you, um…sometimes I fall behind on some of the new drugs because I really could care less. They're, they're, I already know how they work because they're not any different from the other drugs, really, and it's just another version of the same class of drugs that have been out, so in that sense on some of the testing and stuff like that, I may not come out stellar…I'm a concept person, more than anything else and I already get their concept and I understand it and sometimes, you really do need it. You know, we're really good at emergency medicine, crises and things like that—breaks, broken bones, et cetera. I think we're pretty good with, but um, for the most part, that's not a big part of my practice and I respect modern medicine and I still practice it and I still prescribe drugs and I maintain that."

Much like this alternative physician, T4, a traditional physician acknowledges that traditional medicine is best for these types of emergency, trauma type injuries:

> "You know, certainly there are some things, you know if someone has a um, they cut their foot off with a lawn mower, they probably want traditional medicine to be able to take care of the bleeding."

Alternative practitioner A2 also acknowledged the legitimacy of oncology.

> "Well, I think as far as standard oncology, I think standard oncology works quite well in certain diseases. I'm not discounting that at all. But, if you have a disease

> that doesn't have a very good outcome, then I think you should do whatever you can to get your best desired outcome, maybe."

This practitioner acknowledges both the usefulness of the opposite branch of medicine and of his own, arguing that when traditional medicine methods failed to produce results, patients should try alternative methods, such as the ones his clinic offered. Similarly, the traditional physicians did acknowledge that CAM had benefits in the palliative sense as a complementary therapy or to relieve pain or when all other medical options had failed. All of these medical workers agreed that it was very effective as pain relief.

T7, an oncology nurse, expressed positive feelings about alternative medicine's benefits although not as a primary treatment:

> "Yeah, I think eastern medicine and western medicine have their place together. It just depends on what is wrong with you and what your goal is. If you have terminal cancer and your goal is not to cure your cancer, then by all means, please do all those other things. If your goal is to kill cancer cells, you won't do it that way. It kinda depends…depends what method it is. I know a lot about, I mean, I've used acupuncture myself. Like, I think it's amazing and we have massage therapists that'll come to the hospital and massage our oncology patients who do specifically oncology massage—best thing ever—Ok. Um, I think alternative medicine has a place, but when it comes to actually, I mean, you can use acupuncture to help with the pain from chemotherapy or neuropathy or nausea, but it's not gonna cure your cancer. But, what I've seen with oncology patients is that, well, complementary alternative medicine can do amazing things with their side effects, it can do amazing things to really help them cope with things, relaxation, it can help with nausea and pain control—it's great for those things. Patients who rely on that medicine to cure the disease are not…we've had really sad problems with that. Young, young people, instead of having surgery or chemo ended up dying from their disease, so. It depends on outcomes and goals. If you have a treatable cancer and you want to get better, yes. The chemotherapy, radiation, western option is the best for you. And that's what we do with most patients. But, yeah, if you have a terminal disease and you're miserable, I see no reason to pump you full of chemicals that are gonna make you sick, so it just kind of depends on outcomes and goals. But yeah, if you have curable, treatable

> cancer and you want to not have cancer anymore, then yes, you really should go the western route."

T7 made a reference to alternative and traditional medicine as "eastern and western" medicine and believed that alternative medicine, or Eastern medicine, had it's place—that place was just not the curative one. She is dismissive of alternative medicine because it does not utilize the methods that she feels are superior—traditional, evidence based medicine and science—and therefore does not feel it is suitable as more than a palliative or complementary measure. Patient navigator T6 expressed similar feelings about alternative treatment being beneficial to patients in some regards, in spite of her feelings of distrust toward those that offered it.

> "I think there's a benefit to it. Now, how do you measure those benefits? I don't know. But I think there are."

Much like her wish for standardization of supplements so that outcomes were measurable, she expressed a desire to make the benefits of the treatment measurable. Nonetheless, she acknowledged the benefits of it and, in spite of her reservations about it, overall endorsed it as having a place in treatment.

In spite of some of these statements that created a picture of alternative and traditional medicine being accepted by one, there were other indications that this was not the case. Some of the Alternative respondents felt that a local prestigious traditional cancer treatment center had an organization that threaten and shut down their practices if they presented themselves as someone who treated Cancer patients. Upon explaining this, one respondent declined to be interviewed entirely for fear of being discovered, despite being assured anonymity. While one respondent at another local facility seemed

suspicious, causing the interview to be very short and formalized, another respondent at the same facility was very forth coming about this information. According to this practitioner, A2,

> "With respect to our clinic, there's a lot of negativity out there, unfortunately. Like, if you're studying alternative medicine and other of these areas, you have a group that really hates this whole idea. This is an organization called the Skeptics Society, so they are really trying to, essentially, get us out of business. They are a very unified, sophisticated group of people that blog all the time, have a lot of connections and, if you google us, there's a lot of negative things they've written and it gives absolutely no numbers and they've even infiltrated newspapers, like USA Today to get down pieces on us, so it's unfortunate. Patients read that and they are really scared and they don't wanna come here, so the Skeptic Society hates…they really hate people like Deepak Chopra, they hate people like Tony Robbins, they hate people like Dr. Oz, they hate supplements, they hate acupuncture, they hate yoga, they hate Cirque de Soleil, I think. *Laughs* OK? So, if it's not standard of care, or like some AMA thing, that it's just crap. So, forget about having any soul—they're all atheists, you should have just kinda do what you're told. That's unfortunate. Not a fun group of people, in my opinion." *Laughs*

Nothing like this was mentioned by respondents in other cities, but from both those who agreed to an interview and those who declined, there was concern as to why I was interviewing and most said they were or had been under scrutiny from representatives of traditional medicine in one way or another. According to A1, he was initially interested in nutrition before he went into medical school, but, even that was met with skepticism:

> "Um. I, I liked nutrition before and I tried to learn that before I went into medical school. Of course, that was beat to pieces, denigrated and laughed at. Ridiculed…The people who, they, you know, you get plenty of vitamins out of your food, anything else is just expensive urine. That's what you're told, which is a declaration of not understanding health. You could make that same argument about water. You know, it goes in, goes out. That's what life is. It's a process. But, so, I went from there, uh, to practicing medicine."

He also reported similar polarizing experiences after successfully treating cancer patients.

> "you know I had one patient that had uh, prostate cancer, small cell cancer of the prostate is extremely aggressive—1 out of 500 prostate cancers are that type and, 99.5% of people who get it are dead within 3 months of diagnosis and, nobody's ever lived past 9 months and his was biopsy proven in the prostate and the lymph nodes and um, he wanted to fight it. So, he did a lot of research, I did a lot of research and uh, on all the ways to fight cancer etc. About 2 ½ years later, he got an email from the number 2 prostate doctor in the country, whom he had visited like the year before and never did anything of what they had to say because it didn't make sense to him and, it was just palliation, basically. And uh, the email said uh, his name's Wayne, been a friend of mine for many years, he says, "Dear Wayne, I was wondering, glad to hear your doing well, I was wondering if any of the treatment modalities you used, did you feel was of particular value?" and he said, "I think the radiation was beneficial early on. I don't think the chemo was ever of any benefit. There's no evidence to support it. However, I take over 60 tablets a day of different nutritional supplements." And his email comes back "thank you very much." End of conversation. And that is the universal response. I mean, I talk to docs all the time and tell them about how this works, how that works, they go "wow that's really interesting," and they walk away and do nothing different."

A1 provides another example of traditional medical practitioners being dismissive of alternative treatment, even when there is evidence of success with its use. When asked why he felt this was the case, A1 stated:

> "You pick whatever reason you want as to why. There's probably a lot of reasons and it's probably all of 'em, you know, for each one of them, they have the same reasons, but, none of 'em are valid. You know, once you learn this, it, it's not only empowering patients, and you get better results without doing damage, but, as far as I'm concerned it's your moral obligation….I just have a bigger tool box, which includes allopathic medicine and a lot of other stuff that don't make it into the medical literature and they never will, especially if they're effective. If they're not effective, you bet. If you want to get published, the fastest way to get published is to do a trial on a natural substance and have it fail. Even if it's a really mickey mouse study, they will publish it in a heartbeat if it fails."

A1 feels that traditional physicians never acknowledge any sort of success with alternative treatment. Even if alternative practitioners try to get studies on their work

published in medical journals, the only thing that will be published is something that is unsuccessful. In this way, traditional physicians are gatekeepers of medical knowledge and, according to A1, and will not admit that alternative methods might work. According to this physician, these experiences extend not only to practitioners, but to the patients who utilize alternative medicine. Just as in the literature, some patients felt that they could not share their use of alternative therapies with their traditional physicians.

> "I had one of my patients say she pulled out some stuff that she was taking for her arthritis and the rheumatologist says "I don't believe in that stuff. I don't like the way Dr (Self) practices" and put it straight in the trash. So, she said, "well, I can see I won't be coming back here again," you know. So, so, it's, patients learned about that glucosamine and chondroitin or whatever they're doing for their joints—exercising—they learn about that, rarely from their physicians and yet they're doing it. There's a whole lot of people doing alternative medicine and often don't tell their doctors cause they don't wanna hear or be ridiculed for it and they think doctors have knowledge they don't have, but they don't have it all. And they don't seem to be willing to try it and so, in that sense, I think it's been very empowering for patients, um, but, there's um, they find that attractive, they're tired of being subject to, and that's all it was before, this big authoritarian that tells them what's right and you know, asks questions like "what medical school did you go to?" as if that's saying something, you know."

This physician touches on this idea that there is a mainstream way of thinking. Science is the dominant paradigm and anything that goes against it, whether it is the practitioner or patient suggesting it, is met with resistance. There can be only one correct way according to this dominant paradigm and it is so embedded in the culture of medicine that anything else seems inherently wrong.

The mainstream

When asked why he went into traditional medicine, T4, an oncologist at a large traditional treatment facility stated:

> "I guess it's just, it was what was expected of me. It was my traditional um, training. You know, going through high school, like a lot of physicians, we have dominating parents that wanted us to be doctors and so, you know, from an early age, I remember watching Marcus Wellby with my mom when I was probably 5 or 6 and throughout growing up wanted us to go to medical school and so that was probably a huge influence. But you know, in terms of going to medicine and traditional medical school or maybe becoming a doctor of osteopathy or some other alternative, I guess I was always just part of the mainstream."

The "mainstream" to him is traditional medicine and generally, what is accepted as the norm. When asked why he felt patients prefer traditional medicine, he again mentioned the mainstream, saying that it was most likely because that was what was expected of them, because it was "the mainstream."

Similarly, T7, an oncology nurse, when asked the same question, stated:

> "Um, when they do prefer it, they see it as being science and the American western way of doing things, the rational way of doing things. Or um, they wanna do, you know, everything they possibly can, so they wanna go for the most, you know, technical, I guess. You know, the thing that's the most likely to fix things or you know, yeah, they just see things as being "that's the way that it's done," I guess?"

Here, T7 is using this same idea of the "mainstream" when she says "that's the way it's done" and affiliating this with rationality and being technical. She explicitly states it is "science" and "the American Western way of doing things" and these characteristics are enough to make it the obvious choice which she later went on to call "the standard."

A4, an alternative practitioner, had similar thoughts on why people prefer traditional treatment:

> "Um, I think you know, it's kind of the status quo, that it's what's known, it's what's comfortable, it's the scientific method and I think a lot of patients are drawn to that, generally….I think that, the gold standard for medicine has been Western medicine."

All of these ideas suggest that science is the standard, the mainstream, the norm, when it comes to treatment. Beyond that, it is promoted as the best and the highest quality for medicine. It is the first and obvious choice for patients and this is why they would, and by extension, should choose traditional medicine. Anything else (as indicated in the story of A1's patient and his experiences with traditional physicians) would be unacceptable and stigmatized. Indeed, some of this does show itself when physician's discuss why they believe patients prefer alternative medicine.

When people do prefer to utilize something outside of the standard, physicians and practitioners usually cited the following reasons: the harsh drugs involved in traditional medicine, the preference for something that is more "natural," a desire for more personal treatment and care, word of mouth about success with some other method, and a lack of trust in the health care system. While some of these statements were value free, at times, there was still a stigmatization toward deviating from "the standard" of traditional medicine.

Chemotherapy and cancer treatment is a very difficult process, due to the unpleasant side effects of the harsh drugs patients take. T2, a nurse at a traditional treatment center said that, when patients choose alternative medicine, it is in an effort to avoid the discomfort that comes with these aspects of traditional treatment.

> "Because they don't wanna go through the harsh treatment, you know, because, like I said, those drugs are very powerful drugs. You're gonna get, I guess, how can I word this? It all depends, I think it all depends on the person itself because, you know, everybody's body is different. You know, some of them tolerate the chemo. Some of them get deathly ill. Some of them don't. Some of them go through it like a breeze. You know, you're gonna lose your hair, you're gonna lose the taste that you always had. Everybody um, every single person that I've spoke to, like I said, when I see em down the road, 3 or 4 months later, they'll

> say to me, "I have no desire to eat, you know, because there's no taste." Because you lose your tastebuds, you know, you lose your smell. There's stuff that gets to you that you never thought that would get to you, um, I've just heard so many different types of things and so many different side effects from so many different drugs, but you're gonna have that when drugs are like that. They're so powerful because they're in there to do that one thing and they're doing it, but at the same time, they're killing all this other stuff and I always tell them, "look just focus on the other things, just think, next year at this time, you'll be able to taste the tortillas?" you know? Laughs. We're doing this because, you know, you wanna prolong your life, you know? So…"

She sees this aspect of treatment as a necessary evil. It is part of the price you pay for eradicating cancer. The drugs may have side effects, but those side effects are because of the power the drugs need to be able to fight the disease. In contrast, A1, an alternative practitioner notes that, while these drugs are powerful and the side effects are a deterrent for patients, he does not seem them as a necessary evil for curing cancer or even as something that is very likely to.

> "I think people are um, I think people are waking up to the fact that all these drugs have tremendous side effects. And uh, you know, the drug companies opened up these commercials several years ago and people started listening to them and what they heard was a whole list of side effects and then seeing "and death" at the end of it and they're going, "why would I do that?" and they're not, they're not happy with it. And every time they go to the doctor, they get a new drug that's added to their list of medications and the price of those are…theft, you know, it's highway robbery."

This physician further discussed a patient who has Crohn's disease that, if treated with traditional medicine, must get a very expensive monthly injection--$24,000 per month. If treated with alternative medicine, this patient requires a very small dose of a drug and mostly dietary changes, which is much cheaper and can actually reverse the condition. This idea is met with skepticism and disbelief from traditional medicine practitioners who are only committed to evidence based treatments.

> "And they, they, all they read is their literature, so they're never gonna know. The other reason is, what percentage of cancer patients are cured by chemotherapy? 2.2% Really? Why would you wanna do that? So, often times, you know, one of my patient's said she was listening to her husband's oncologist who told him, he said, "we can't cure this cancer, but we can treat it like Diabetes" and all of a sudden, she said, I understood."

From his perspective, not only is treatment harsh, but also, it is very costly and not very successful. He feels there are options that are easier on the body and more natural solutions to these health problems:

> "The other thing that came along was the Paleo Diet, which changed the entire paradigm of health. Basically said, in a nutshell, all these diseases that humans get as we age or even nowadays in infancy you can get loads of stuff are manmade, cause when you study hunter gatherers, they don't get 'em. I mean, cancer is virtually unknown. Occassionally, they'll get a toothache or something, but that's really rare. And so, they don't get osteoporosis, the cancer rate is virtually unknown, they don't get diabetic and they maintain their functionality in much more of a square way you know, and then, boom, one day they're dead. Hunter gatherer's die almost universally of one of 3 causes: infection, trauma and in their sleep. Now, modern medicine, we're pretty good with infection and trauma, but we're pretty bad with dying in your sleep as an effective functioning individual, so I actually have a theory of aging that explains all that. It has to do with organ reserve and getting well with all your systems at the same time because you're in harmony with your environment and, more importantly you're in harmony with your genes instead of living in contempt of 'em, which we do now. You know, eating foods we're just totally not designed for, we have a hundred times more heavy metals in our bones than our ancestors did 2000 years ago, so…That really changed my way of thinking and why I sort of moved into this. So, I think patients see that, um, that difference that's harmless to them and it's using something that makes sense to them and it's part of a template that makes very good sense to them. Respect how the body's designed and it'll perform terrific. Once they understand how healthy hunter gatherers are, then, the goal becomes much more lofty. And then you recognize it's obtainable, far more than what you would ever expect. So, yeah, it's crazy, but it's that simple. And I think that's why patients are looking for it."

This practitioner also thinks that patients are seeking out natural options—things that are in harmony with their bodies rather than harmful to their bodies and taking them back to their natural, "unfettered by manmade products" state. This model of care makes

sense to them and those individuals seek out treatment that falls in line with it. T7, an oncology nurse from a traditional treatment center felt like this was a draw for some individuals, as well.

> "for some people, they wanna do the natural thing. For some people, they're really big, I've always eaten vegan and I run every day and I'm not gonna put those chemicals in my body and I'm just like, well, I'm sorry. Um, there's that and there's people that are in denial of the severity of their illness and think that, "well, I had this thing once and that thing once and the chiropractor fixed me," but no, it's different. So, it kinda depends on the person, but it's a lot of "I don't wanna put those chemicals in my body. I'm afraid of what those chemicals do. I've heard terrible things about chemotherapy and terrible things about radiation and the side effects they have" which are awful--I'm not gonna say they aren't--and people who are kinda anti-science, anti-big pharma, big conspiracy--also not gonna say that they're great--but those are our options right now. So, big pharma and the conspiracy and the people in denial about the severity of their illness. 'These herbs will make me better, don't wanna face going to the hospital and feeling like a sick person.' You know, nobody wants to be a sick person. So, it kinda really depends."

This practitioner notes that not only do people desire to stay natural and avoid chemicals and drugs with side effects, but they also are minimizing how sick they really are and trying not to acknowledge it or fully accept the sick role. This does fall in line with the literature regarding the way that some people choose to handle or not handle their diagnosis of cancer. Treating it makes it a reality and changes the focus of their efforts to become well—going to the hospital for heavier drugs means acknowledging their illness and taking on the sick role, which means other roles would be limited and made secondary. Additionally, she points out that people who opt for alternative medicine do not have much trust in the traditional health care system. This idea was repeated by patient navigator, T6:

> "I sometimes think some patients don't see hope where they wanna see it at different times. Um, and then, just not trusting the health care system. Uh, people

> like the easy out. Sometimes health is not always easy. I mean, eating right and exercising is not always fun either and, it's hard, you know. And sometimes I think they see that natural remedies are the easier way and that kind of thing. Um, yeah."

Here T6 expresses some of the same ideas previously mentioned regarding distrust of the health care system and people's preferences for natural remedies. However, T6 states that people prefer the natural remedies because they see them as an easier route to good health than traditional treatment options. She compares going through traditional treatment to dieting and exercise—for her these may be difficult, but they are necessary pathways to good health and doing something else is likely motivated by the desire to cut corners.

In contrast A2 and A4, alternative practitioners, felt that people opted for alternative medicine to get the personal and caring touch that patients often feel that traditional medicine is lacking. According to A2, patients prefer alternative medicine because

> "it gives more than what you usually get at that cold doctor's office. There's just a lot more caring and they're seeking to have better outcomes at the end of the day, right? I mean, in this setting of Cancer, a lot of cancers are pretty dismal, right? So, if you can extend lives, for somebody, doing something different, giving them a better quality of life, that's why they come here, right?"

Similarly, A4 stated:

> "I think part of it is they, they like the healthcare that's designed specifically for them. Looking at their whole body and taking the extra time in listening to their medical history that's not done anymore. Um, a lot of times, I just listen to people and they feel better. So, I think some of what happens is that personal touch that you can get from it. I think, also, as a practitioner, we don't, you know, we don't take care of lab results, we take care of humans. And every case is different, in my eyes. And I think a lot of times, patients feel like they're lumped into "I'm this diagnosis" and they lose their identity in that, you know. They, they, kind of lose their say in what kind of thing happens to them to, so that's usually when they come to me."

Both practitioners feel that patients come to them to get healthcare that is designed specifically for them and to have physicians who they feel genuinely care for them. The personal touch and being treated as an individual does a great deal to make people feel more at ease at a time when they feel very uncertain about their futures.

Several of the traditional physicians felt that people were primarily steered toward alternative medicine by word of mouth. According to T7, patients who had been ingesting baking soda to restore their Ph or taking silver to cure their cancer did so because of local lore in the region where they lived. T2 also believed people tried these options because they were looking for an answer to their health concerns and people they knew believed they had found an answer through some of these alternative methods. T5 echoed these sentiments, saying:

> "It's usually word of mouth, I would think. You know, they've talked to somebody that's tried it and it's, it's, I think it's usually word of mouth or some people are just willing to do whatever it takes to see if they can get a cure, so they're willing to take that risk if they have a low prognosis. Or, it may not even be the case of a low prognosis, they just, they're willing to try it to see if it works."

Alternative practitioner A3 acknowledges that it is generally word of mouth that initially sends patients looking for his clinic—in fact, he says that he will not accept patients unless they have followed the standard protocol (chemotherapy or whatever else their oncologist might have recommended) first. However, he feels they have come to see him not simply because someone else said it would be a better option than chemo, but as a last resort because "mainstream" medicine has failed to cure them and, in their quest for survival, they have opted to try something else—his clinic--which he perceives to be the future of medicine.

> "Because, these patients who we see, most of them are told there's nothing can be done for them and they are sent to hospice to die, so they are looking for some other ways to save their lives. This means that the standard of care failed, in their cases and they are looking for something else available—future of medicine, to help."

Regardless of why these physicians felt patients preferred their own or the opposite branch of medicine, most of them seemed to indicate some negative feelings toward the branch of medicine they did not practice and, at times, the patients who chose them. However, when asked if they thought their branch of medicine and methods of treatment were superior, very few said they did. Even when they did say their method was superior, they still gave some credence to the other method, such as in the case of alternative practitioner, A1. When asked if he felt his method was superior, he stated:

> "Oh, it's absolutely superior…And, by that, what I mean is, if somebody has a big tumor load and they don't have much time, I always send em to the oncologist. They don't have to do what they say, but they can. And, I'm not here to try and corral people or put blinders on 'em at all. Um, you know, I want them to research all the methods and then decide. Um, but, if somebody has a big tumor load I think the best thing for them to do is get big ugly chemo and let's knock that down to the smaller we can get it. And you don't have to keep doing it for as long as they tell you to. You can stop it at any time and probably do concurrent vitamin C so it doesn't destroy them in the process, it doesn't destroy their immune system, which, any oncologist will tell you kills the last cancer cell, is your own immune system. K? But that's the first casualty in chemotherapy, oftentimes because of the chemo, but the vitamin C really helps prevent that and potentiates the cancer cells from being killed, so, and of course that works with radiation, too. One of my patients had a lung cancer, has a 2 percent survival rate and so, he comes here and says, "what do we do?" and I says, "well, go visit a radiation oncologist, y'all get a game plan and then, every day before you get your radiation, come here and get an IV of vitamin C." So we opened up early, opened up at 7:30 and this guy came in and got his IV vitamin C and drove straight to neighboring city and got his radiation. 29 treatments, 29 IVs, 3 months later, they did a CT pet scan as dead as a doornail. That oncologist actually called me—we'd had some fun conversations before because he's been around long enough and is open enough and more right brained and recognized the validity of these treatment modalities, at least the thinking behind it. First words out of his mouth was "well, your vitamin C worked" Now, we don't know that, but it was

> really nice validation and very unusual. His partner over there said uh, made a comment to one of my patients that I had forsaken my hypocratic oath. So, you can see the difference in the mindset that people have and the response to what I'm doing."

Here, A1, again gives us an example of a negative experience with practitioners of the opposite branch of medicine, but couples it with a positive one, where an oncologist validated his method of treatment. While A1 is telling us that he believes his method is superior, he also does not say that traditional treatment does not have useful properties and he also does not discourage patients from exploring and using those options.

Similarly, T5, a radiologist, stated that she felt traditional medicine was superior to alternative medicine because there is certainty that it works and she cannot say the same about alternative medicine. However, she does acknowledge that she also cannot disregard alternative methods entirely, because she has not had much experience with it. There is an element of the unknown that keeps her from saying it has no merit, but she still feels that what she knows is better than what she does not.

In contrast to these two physicians, alternative practitioner, A2 was the only physician who said no when asked if his method was superior.

> "No, I mean, I think we give a, we do great health care. I can't say that we're superior because we have so many treatment centers out there. We've got hospital down the street that is number 1 in the world and they have certain things that we don't have, obviously, but we do certain things that they don't do. We do have more freedom to practice our medicine and that's what's so unique. If you're a small practice, you can kinda do what you want. You don't have to ask other people."

His reference to the hospital down the street was to a neighboring traditional treatment center and, in his response, he acknowledges both the attributes and flaws he

feels they have and the way in which his branch appeals to those shortcomings—the freedom to treat people in the manner that they, as practitioners would like.

Most practitioners responded to the question by saying that, whether their method was superior or not depended on what the goal of the treatment was. T7 felt that traditional medicine was the better choice if the goal was to cure cancer and alternative was better suited as complementary therapy or as palliative therapy, to make the patient more comfortable in their final days.

> "Ok. Um, I think alternative medicine has a place, but when it comes to actually--I mean, you can use acupuncture to help with the pain from chemotherapy or neuropathy or nausea, but it's not gonna cure your cancer. Patients who rely on that medicine to cure the disease are not…we've had really sad problems with that. Young, young people, instead of having surgery or chemo ended up dying from their disease, so…if the goal is to cure the disease, then yes. For me, it really is outcome based. If people have terminal cancer, I'm not gonna tell 'em they should do chemotherapy. If you had 6 months to live and you pretty much have 6 months to live with chemo or 3 months to live without chemo, I would personally choose the 3 months option. I would prefer to live feeling better and not in a hospital. That's not my decision to make. I can only tell patients what I've seen with other people."

T7 not only feels that traditional medicine is a more suitable choice than alternative for curing illness, but also says that people who rely on alternative therapy, alone, at times, do not survive. Interestingly, alternative practitioner, A4, feels that, at times, traditional medicine—specifically, hospitals and doctors making mistakes or causing more harm to patients due to staff errors or infections that manifest in the hospital--can bring about the death of patients. Her response when asked if she felt her branch of medicine was superior was that it was neither superior or inferior to traditional medicine.

> "Um, I'd say that, that I think, starting from a natural approach, with the concept of bringing your body back to its own healing properties, um, is a good place to start. I don't think that Chinese medicine is the end all, be all and I don't think that Western medicine is either, but I think that, in terms of starting from somewhere, it's a good place to give it a shot and, and then make your decisions from there."

A4 feels that it's best to start from the natural, more holistic approach and then, if needed, use traditional medicine. In her view, neither branch has all the answers to health.

In spite of these conflicting views regarding the legitimacy and soundness of the practices of the opposite branch of medicine, there are those who not only claim that there is a place for both branches, but that they would prefer to work together.

One large prestigious hospital has a department of alternative medicine at their facility and, while traditional physicians there may not be very knowledgeable about the opposite branch of medicine, the physicians there seemed to be relatively supportive of some of those methods. In fact, A4 attends a yearly training at that facility and cites it as positive because it helps the allopathic branch of medicine to be more accepting of alternative methods.

> "I tend to do, in that sense is, I work with the doctor. So, whatever they're working on, we work together, rather than working against each other. So, in terms of education, you know, each year I go to big hospital and do more training for acupuncture, massage and yoga—they have a yearly thing for that, so um, and that's almost a bridging of everything else that's out there that works that um, big hospital really trusts. And that's good because it opens the door for Western people to be more open to what I do. Keeps me up to date on what else works and gives me some insight to some of their treatment plans, too."

Likewise, A4 notes that this helps with her understanding of traditional treatment methods, as well. She also says that she works in conjunction with the treating

traditional physician, rather than against them. This is in contrast to many of the experiences that other alternative physicians have that indicate a lack of cooperation or even having their patients hide their use of alternative medicine from their traditional physicians—an action that could have tremendous consequences, since many of these drugs and supplements can counteract each other. When asked if he has ever had any of his patients conceal their use of allopathic medicine from him, A1 stated:

> "Sure. I have. And I try to discourage the secrecy of it. I tell 'em, I'm not here to direct your life. I'm here to give you more options in life and help you lay that out. And so, if you're doing that, I will work with you, you know, I have vegetarians come into my practice and I'm a paleo guy, probably one of the biggest carnivores around. You know, I don't even get on my patients that smoke, you know, even after several years of me trying to get 'em off and I'm usually pretty good at doing that because they won't come back. And I can do more good being less rigid."

A2 is more focused on having an open relationship with his patients than dictating how they live or what kind of treatment they utilize, regardless of his personal feelings about these things. When asked if he felt there was a way to resolve the feeling that this type of secrecy of patients or this polarization between the two branches of medicine, A1 responded:

> "Yeah, there really is. And I've been sort of planning on lecturing at one of the tri county medical meetings about alternative medicine and the first thing I'm gonna do is show the 4 parts of the brain as the model--it's very accurate and very useful and we tend to marry people to help us complete the circle. Cause if one is not being used, there's gonna be trouble down the road and so, what, what, I've realized is, you can marry your mirror image and have no love and there's often very little respect for the other person's way of thinking, but if you recognize your own deficiency and the other person's virtues that they bring to the table, then you get mutual respect and you realize what each one brings to the table and each one loses their arrogance. In fact, that could happen with modern medicine. You know, how do you chose a car? Well, the engineer says 'I look for good engineering and I look for good workmanship,' the concept person. The

> artist over here says 'I like cool cars, I like unusual cars. I like to enjoy the experience of driving them.' The one down here, categorical and sequential says with authority, 'I choose, I check consumer reports. And the rhythm and harmony, the right basal person down here, says 'I have the same car as my best friend, only hers is blue and mine's red' and there's not a wrong answer there. And until you listen to the engineer—well, of course that's what you do and then you listen to the others and you think "oh my gosh, they're all valid too" That awareness, that opening up of the mind can happen. It just needs to be shown and yes, modern medicine is so corralled, they have no idea. But that can happen. I have to believe that. Um, because I was one of them."

He feels that the primary reason for this polarization is the way people tend to utilize one part of their brains more than others, which affects the way they think and what types of ideas appeal to them. He feels if people were more aware of this, they might be more willing to venture outside of their comfortable ways of seeing things and find the value in other people's perspectives, along with the recognition of their own shortcoming. Through this awareness, he feels mutual respect would come and this could potentially minimize this polarization between the two branches of medicine.

Throughout the interviews, it became apparent that a great deal of polarization exists between alternative and traditional medicine. Alternative physicians felt that traditional medicine did not have the type of flexibility in treatment and personalized care that their own facilities had. Traditional physicians felt that alternative medicine was not evidence-based and lacked standardization. Much like the information in the websites for the different treatment centers, these physicians showed some knowledge of the criticisms against their particular branch of medicine and acknowledged the shortcomings of their own type of medicine. While alternative practitioners had a background in traditional medicine and were very knowledgeable about it, traditional medical professionals had an admitted lack of knowledge on alternative medicine and

tended to formulate their opinions based on the most extreme examples of alternative medicine, rather than anything the alternative practitioners interviewed actually practiced. Both branches acknowledged that there was a place for the branch of medicine they did not practice, although traditional physicians tended to give far less credence to alternative methods than alterative physicians gave to traditional methods. All physicians acknowledged that traditional, western medicine was the more accepted type of medicine and was seen as "the standard" for medicine in the U.S. As individuals who deviated from that standard, alternative physicians discussed feeling stigmatized and discriminated against by the traditional medical community and, as a result of the distrust created by these experiences, obtaining interviews with these individuals proved to be very challenging. Many of these practitioners felt that working together and utilizing integrated medicine would be best and were optimistic about the possibility of this in the future.

Role in patient care

When it comes to patient care, physicians see their roles differently, depending on which branch of medicine they practice. Alternative physicians see themselves as partners in the patient's care and a place where their clients can talk about their problems and be emotional with them. A1 characterizes his relationship with patients in the following way:

> "Very personal, very friendly. Um, I, I listen to my patients, they bring me information that they found on the internet, whatever, um, concerns they have about their health and I listen because I learn from them and I'm not afraid to look up what they've brought me. Medical school was a beginning and only a beginning. And that's the way you really need to look at it, but, um so, it's very, I give my patients a lot of respect. I learned they can actually think. *laughs*. And

> allowing them to participate, intellectually, in their care makes them a much better patient from my perspective in terms of uh, uh, health benefits."

A1 characterizes his relationship with his patient as not only friendly, but educational. When patients ask questions, it requires him to learn something in order to provide them with the information they seek. He emphasizes the importance of respecting patients and allowing them to participate in the treatment process as a way to ultimately improve treatment outcomes. In this way, the relationship with his patients is mutually beneficial to the parties and is a partnership, of sorts. Similarly, A2 also stresses the importance of the practitioner's role in patient care:

> "Um, well, I like to think of myself as somebody that sees the whole picture. A lot of people are doctors, but they're really stuck to the guidelines they have. But there's so much more than that. There's a whole person. You interact with a patient. You have to really be their coach in a way, if you really want this to work. I just kinda look at it with them with an open heart."

A2 describes his role in care as that of a coach and emphasizes the emotional aspect of interacting with the patient, beyond just treating their illness. He feels that traditional medical doctors tend to be limited in the way they provide care, based on their guidelines limiting their thinking. His emphasis is on treating the whole patient and keeping one's heart, as well as mind, open.

This notion of emotional care, along with the idea of a partnership, was also emphasized by A4.

> "Um, I'm a partner with them in their, their strategy. A lot of times, patients come in and they tell me their story and uh, I'm more of a triage person. I figure out what's going on first and then we figure out which discipline will—if just one or several—will work the best for them. That's how we do it…it's very, it's very personal, uh, it's a very intimate bedside manner, you know? We cry together--I'm in the room with these patients for hours at a time. I'm somewhat of their counselor and um, and friend. And uh, sometimes, that's tough for

> boundaries. So, the patient feels, definitely connected and I'm part of their, like a part of their dream team."

She describes her relationship with patients as being partner in crafting their treatment strategy. It is not simply her dictating treatment, but rather her acting as part of a team with the patient and their other physicians. As previously mentioned, she often works in conjunction with the traditional physician seeing the patient, so that they are not working against one another. As part of this team, she experiences a great deal of emotional connection to the patient and considers herself a confidant and friend.

Alternative practitioners, such as A1, would sometimes offer services where patients had their cell phone numbers and could call anytime. The practitioner would spend more time, one on one, with patients in an effort to get to the cause of their health issue and try to treat that, which, he was quick to point out, was not something traditional medicine would bother to do. He referred to this service as being a Concierge service.

A4 mentioned that she knew of traditional physicians starting this Concierge service as well, independently of their work in hospitals or private practices. It was a way for physicians to give patients personalized care and spend more time with them than they were able to give in their traditional office settings, within those time constraints and roles. In this way, this was a sort of solution to the problems some practitioners had acknowledged with their branch of medicine, but it was one that was also monetarily beneficial to these physicians.

Just as the alternative physicians had mentioned, some of the traditional physicians also mentioned a movement toward concierge doctors and patient navigators to alleviate some of the shortcomings of the system. T4, in particular, said:

> "I think that is evolving. You know as, patients, there's a big emphasis now, looking at personalized health care and personal health records and personal, you know, individual, you know individualized treatment so we don't you know, run people through like masses and everyone gets the same prescription for a drug or a treatment and so, um, there is a huge emphasis on customizing treatments and treatment plans and, you know, even nutritional plans. You know, looking at the holistic patient who um, to address their well being. You know, medicine, traditional medicine is only part of the circumstance. You know, there's a huge mental and emotional component of treatment of patients. Patients are not necessarily machines or widgets that we tweak and and oil and send them on their way. You know, there's this other component, but…and many factors that many traditional doctors tend to ignore are, or whether they ignore purposefully or are just ignorant, but you know they're factors in patients homes and lives that effect their treatment. You know, their ability to purchase medicines or seek therapy or see a doctor or some other health care professional, so there's many many factors."

This physician has echoed the very sentiments of the alternative physicians in talking about treating the whole patient and taking all other factors into account, not just the illness. He emphasized this importance and noted it was stimulating a movement toward both concierge physicians as well as patient navigators—individuals who would provide all aspects of this type of personal care except for the actual administration of the treatment to patients, as part of the service included with treatment at these facilities. Once such individual, T6, was interviewed.

> "One of the ways I describe what I do to patients is, I provide a medical concierge service to them and connect them to medical resources not only within (hospital), but within the community. Um, I also uh, help assess them for needs that can interfere with their care, such as financial needs. With cancer there's a financial toxicity that's as bad as the side effects of chemo and you have to almost address that right up front with them because that's their biggest worry. I address their education needs… and then I'm also that one point person that I

> follow them from the time of biopsy—I follow 'em to the surgical phase, to the medical oncology phase with the chemotherapy, into the radiation phase, to survivorship. So, they have all kinds of different doctors and different nurses along the way, but I'm that one consistent that stays and you know, I assess if they have issues with transportation, family issues—And, I'm a free service to the patient. You know, the goal is good outcomes for their care as well and you know that life happens and you've gotta address the patient's needs with other things to make sure they jive with each other before their treatment."

T6 literally defines her job of patient navigator as a concierge service for patients, one that, again, takes into account every part of the patient and their lives and largely follows the description of what alternative practitioners see as part of their duty in caring for their patients. Even the emotional aspect of the job is very similar, as illustrated in the following quote from T6:

> "One—we're working on a different tool--but one thing I assess them for, like just when you're told you have to have a breast biopsy it's scary. A lot of women'll get their mammograms and they don't really think, 'I'm screening for cancer,' but that's what you're really doing. So when we tell you ya gotta come back and have another film or an ultra sound or maybe a biopsy, then it becomes very real and that anxiety level goes up to here and one of the big things I try to do is to educate and let them know what to expect because they have all this anxiety. Then when we are waiting for these results, then I talk about, 'let's talk about the worst case scenario.' And let them see that there's hope there and that we're gonna be there to help them and that they're not gonna be alone in all this process and that 'what's your biggest worry?' that's the one thing we focus on. 'What's really bothering you right now? Let's address that now' so they can, my goal is so they can sleep at night. So they're not worrying about something that's unfounded. Cuz you know, we can come up with all kinds of horrible things that may not ever even apply to you, but then that person spent all that negative energy which doesn't help 'em at all."

This patient navigator feels that she does take the role of supporting and educating the patient throughout the treatment process. She is trying to assist them in any way possible, attempting to relieve their stress and fears and acting as a counselor.

While all practitioners, alternative and traditional, believed they had a personal and friendly relationship with their patients, the process of medical treatment did seem compartmentalized. Each person or department was specialized and assisted the patient with only one aspect of their treatment. Therefore, physicians could not always answer every question in the interview because they didn't stay with the patient through the duration of their treatment, but rather, just a small part of it. T5, a radiology technician, described her role in patient care and healing in the following way:

> "In patient care and healing, well when the patients come in, uh, I see the patient on a daily basis they usually are uh, letting me know what's wrong when it comes to their skin or how they're feeling uh and so, sometimes when the nurse isn't available, I'm there to room the patient, get the vital signs, in order to let the doctor know what's going on with the patient, just in case they need to get them a prescription or recommend uh, some type of way to treat whatever their complaint is at the time."

Other than her job as a technician, this medical professional acts as a go between for the patient and the physician. She describes her role as very compartmentalized. So much so, in fact, that she was unable to participate in the majority of the vignette portion of the interview (where practitioners were asked about a hypothetical patient and their role in care, step by step, from diagnosis to treatment) because she had no idea how to answer the questions. Similarly, traditional physician, T4, describes his relationship with patients:

> "I mean I see patients, you know as a radiologist, many radiologists have no contact with patients. They sit behind a computer screen and they interpret radiologic images without having any patient contact. In my particular specialty, in gastrointestinal imaging as well as doing colon cancer screening, um, I see patients and I talk to patients, yes. But uh, I try to maintain a professional relationship. Well, in terms of performing the radiologic exams that require patient contact, you know, I often explain a procedure to a patient, uh, either before or during the procedure itself--what is happening. Depending on personal

> judgement of the patients ability to comprehend or want to comprehend the information, sometimes I will give the patient a preliminary report of what I see, but not all of my colleagues will do that. Some of my colleagues will perform procedures on patients and just tell them that their referring physician, their primary care doctor will get back to them with the results."

T4 explains that, with his particular specialty, many of his peers never actually encounter their patients. He describes this interaction as he experiences it as being one where a procedure is performed and he may or may not engage the patient beyond telling them what he is doing. The rest of the care and treatment process is left to other individuals. The nurses, in particular, seem to have the most personal interaction with patients. Oncology nurse T7 describes her relationship with patients in the following way:

> "Um, well, medical side, I give them medications, um do a lot of teaching about, you know, netropenia- the low blood counts that are caused by cancer, pain management-what to expect frm everything, administration of blood products and high risk drugs. Um, providing social support to patients and their families and, we do a lot of, um, I don't think anyone should die in the hospital unless they got hit by a bus, but we do a lot of that, too. So, a lot of handholding and you know, just listening to people talk is a big part of my job, too. And try, uh, to--since we're usally very, very busy--I try to incorporate that into even talking to them while I'm giving medications, but sometimes, I have to sit there for awhile and, and listen"

As T7 describes it, the education and comfort of the patient falls on the nurses, along with actually administering a great deal of their care. The support they give is not only to the patient, but their families as well. Because their time is in such high demand, nurses try to multitask and fulfill their duties of physical care of the patients and simultaneously fulfill the role of emotionally caring for patients. This emotional aspect was an area that T7 acknowledged many physicians fell short on.

> "We have doctors that always say you should go with the hardest chemotherapy. It's like, "eh, she's 85, maybe not. Lived a good long life, let's be nice to her." And then you have doctors who say, you know, you have this option, hardcore,

> throw every big drug we have at it, we have 11 options of treatment, present them all the options. When it comes to that a lot of people just hear, "I wanna do everything" and choose the biggest guns option without really knowing much about it. Doctors can be really bad at explaining things, so a lot of that ends up falling to the nurses, even though legally, that's not supposed to be our job."

Here, T7 explains that doctors often vary in the way they choose to approach the patient's cancer treatment. Sometimes, the approach itself isn't very mindful of the patient's condition (as in the 85 year old who might not be able to survive the treatment process and might want to live a more pleasant last portion of her life). Other times, the physicians offer many choices in treatment, but are not very good at explaining those options, which leaves the job of educating patient on those options in the hands of the nurses.

While all physicians felt that they had a good rapport with patients and healthy exchanges, all traditional medicine professionals mentioned knowing doctors who were not great with bedside manner. According to T4:

> "I think I have a pretty good bedside manner. You might judge that from just listening to me. And I'm not trying to be—but I've got other colleagues that are very gruff and not very, you know, as they say in medical school the best doctors are you know the ones with the outgoing personalities. They may not be the most educated or the smartest, but patients perceive them to be caring because of their bedside personality. If you're very cold and, might be the smartest guy in the world, guy or girl, and yet you're a very cold person as you interact with patients, uh they'll perceive you as not being very good, despite how your technical skill. The best is when you have the technical skill and the ability to relate to the patient and sometimes that comes with wisdom and a number of people and their own experiences, their educational level, their spiritual foundations, their you know a number of things."

T4 elaborates on the importance of being friendly and having a good relationship with patients. According to this physician, being friendly and having good bedside matter is

an important component of being a good doctor. The best doctors possess both technical skills and are able to relate to patients.

In general, both traditional and alternative physicians saw themselves as a partner with the patient in their battle with cancer. They felt that it was important to be caring and many had close relationships with their patients, where they described part of their job as "listening" and acting as a sort of counselor to the patient. However, there were also physicians who were only part of the process of treatment and either had very little contact with the patients themselves or knew others who never had contact with patients. These individuals often were unable to answer all of the questions in their interviews and acknowledged that the traditional health care system was problematic, in that it created an environment where their time was in such high demand that they could not have these personal interactions with patients.

Perception of patient trust in doctors

For the most part, physicians felt that patients did trust their doctors, though they acknowledged that the amount of trust patients had in them had changed over time. According to patient navigator T6:

> "Yeah, over my whole career, I would say, I would say they're very trusting. Because it's now more of a partnership with your physician, moreso than the physician being all knowing and this is what I'm going to do for you and you're going to follow my instructions, despite whether you understand why or not—that's what it used to be years ago. Then patients didn't ask many questions. Now they ask a lot of questions and um, you know, at the beginning of that contract, you might say that to the patients, you know "this is in your best interest," to do what we know, evidence based, will improve their health, um, and then at the same time, if you have a patient who is doing everything to work against what you're doing the physician always has that opportunity to fire that patient. Does that happen very often? No, but it's very very rare. I mean, I've not seen that here, but in healthcare, that happens."

According to T6, doctors have now become less of an omnipotent figure in care and more of a partner in a strategy to improve the patient's health. This change has led to a change in the dynamic of the relationship between doctor and patient, but it has not done anything to affect trust. This change, along with the implications that it has on trust, is reflected in the website materials that endorse patients "speaking up" not only in making their treatment decisions, but in ensuring that their health care providers are doing everything correctly. Simultaneously, compliance to the treatment plan is part of what constitutes a good patient and a non compliant patient may also have that relationship severed by the physician. Radiation oncologist, T4, also associates compliance with trust:

> "You know, patients have all sorts of choice, I mean, you know patients, patients, you know, there's no contract that says patients must follow a certain, you know, prescription of treatment. Many do, but again, you know, they trust the physicians."

T4 acknowledges this change in the perception of physicians as all-knowing figures to the realization that doctors are regular people who are flawed and make errors and the Internet can facilitate a way to track those kind of things for patients.

> "Oh yeah. I think, you know 30 years ago, people—"trust me, I'm a doctor,"…"trust me, I'm a god?" you know? And today, there are enough physicians and you realize physicians are human, too, physicians make mistakes, physicians do stupid things, and um, people get online. In fact you know, they're looking at ranking physicians and their outcomes, you know, and that's been a big controversy with the doctors. But to, you know, be able to look at your report card and see if your patients live or die or get better or get worse. You know, there are all these things."

In spite of the consensus that trust in physicians is good, there seem to be indications that the level of trust has been eroded over time, both by the materials of the

treatment center websites themselves, the availability of health information on the Internet and the realization that doctors do make mistakes, particularly when "trust" equals compliance and lack of compliance equates to grounds for terminating the doctor patient relationship. Oncology nurse, T1, makes a distinction between her specialty versus doctors and general medicine, In general:

> "I think it's sort of going the opposite way of… I do think it's a little bit different with cancer versus primary care because I do think when you get to like a life threatening illness, people are like, "ok, I need to pay attention to this. I have something that can kill me, so I need to listen to my doctor" um, versus, I think primary care is um, you know they can blow the doctor off and never get the drugs, probably."

T1 feels that the seriousness of cancer and the potential for lack of compliance to kill the patient makes them much more compliant than patients who have less severe conditions. This compliance and heeding the doctor's warnings and advice again equates to trust. This trust looks much different to alternative practitioners. For alternative practitioners, this trust is more specific to themselves, rather than medicine in general. According to A1, this trust is tied to his openness.

> "Oh gosh. That's, that—way too much. Uh, but I'm honest with them, so they know my limitations. Most of my patient's when they go to a specialist, they come back here and go "what do you think." And I will tell you, probably 50-60% of the times, I agree. The other part of the times, I don't, for whatever reason."

A1 tells his patients that he doesn't know it all and, when they seek out advice from a traditional medicine specialist, they come back to him to verify that the information they received was correct and the course of action is one that he concurs with. A3 feels that trust in traditional medicine itself has eroded because the relationship

with physicians is far less personal because patients spend very little time with doctors, a problem she attributes to insurance, among other things.

> "I think people are less trusting because of insurance. Maybe the doctors don't feel like they have much control anymore because it's what insurance is allowing them to do. Or maybe that amount of time isn't enough. And, you know, drugs have way more side effects now and they have all these recalls and class action law suits for, you know, damage and surgeries that go awry and hospitals screwing up, so I think there is a lot of distrust."

A3 acknowledges the same things that others have previously, regarding the perceived problems with traditional medicine and cites those issues as the cause of the loss of trust in medical professionals. Like A1, she also feels the trust patients have is specific to her and acknowledges that, even though there may be all of these negative perceptions of traditional medicine, simply utilizing treatment that is outside of the standard type of medicine requires a great deal of trust.

> "Well, I really think they have to put a lot of trust in me to come to somebody who, that is, um, you know, outside western medicine circus tent. And, also just being, you know, it takes a lot of trust to just stick to a plan for some people, so."

Again we see this idea of compliance equating with trust, but also an acknowledgement that going outside of the treatment that most would see as the norm requires trust, too. This idea of being treated by something that is not the standard can make the trust of the patient tenuous, according to A4.

> "Well, usually, they have very good trust, but this trust could be shaken when they go home and they encounter the other doctors who do not understand the treatment plan and they persuade them to really, I would say, "cut the corners," reduce the dosages of the medications or discontinue some medications, so then, obviously, the mistrust comes from uneducated, uh, eh, medical professionals who are advising patients without really understanding what is the treatment plan."

For A4, it is the polarization between traditional medicine and alternative medicine that causes trust issues for patients, rather than anything he or any other alternative practitioner may have done personally.

Patient trust in physicians is precarious. According to physicians, there are many things that can have an effect on this trust such as health information on the Internet, advice from doctors practicing the opposite branch of medicine, how far treatment deviates from what the patient perceives to be standard medicine and the seriousness of illness. Trust, or lack thereof, is demonstrated in patient questioning of the physician's orders (which, again, is ironically, an act endorsed by traditional treatment center websites), seeking out the doctor's opinion on treatment and complying with practitioner's directives. While medical professionals acknowledge that the amount of trust patient's have in their recommendations has changed, the majority do feel that this has really only changed the nature of their relationship in care to a partnership, rather than one where the physician simply gives orders. Generally, these physicians feel that the level of trust is still good and, the fact that this relationship has been redefined as a partnership means that, if the doctor is displeased with the patient for any reason (typically noncompliance with care directives) they can terminate the relationship just as easily as the patient.

Patient control

All physicians in both branches of medicine felt that patients should have control and feel in control because these individuals have been stripped of all certainty. According to oncology nurse, T7, patient feelings of control are very important for this reason.

> "So important. Even if you just give them… People get…Most people are independent of the world and then they get cancer and they no longer have a lot of those options, especially patients who have a new diagnosis of leukemia. They're with us for between 30 and 90 days, can't leave the hospital. They are in a room. A tiny, not nice room for a minimum of 30 days, sometimes up to 90 days before they can even leave and then they come back in for consolidation chemo for weeks at a time. So, they have had all control taken from them. In the hospital we are supposed to tell them when to eat, when to go to the bathroom, when to shower. You know, we have all these regimens for chemo that are strictly timed and so people get angry or get depressed or they just get mad at you. People can get really angry and I totally understand. All control has been ripped from them. So I think it's important to um, even if it's just, 'what time do you want to take your shower?' instead of 'you're going to take your shower at this time.' I mean, a lot of medications we can't, like the regimen is, we do this and 12 hours later, we do this. It's that way for a reason because that's what studies have shown does best to kill cancer cells. But, anything that is not a strict thing like that just whatever control you can give back to them is so important.."

This idea that patients are in a distressed mental state due to this loss of control falls in line with previous research. However, previous research focused more on the loss of control of the patient's own health and the certainty of their future, rather than the loss of control due to the regimented nature of treatment that T7 sheds light on. T6, however, expresses an opinion more in line with previous research.

> "I think it's very important. You know if you refer back to the breast patient, or really any patient, once you're told you have cancer, the impression that you'll live forever is now gone. The impression that, 'I'm gonna live to see my children grow or have grandchildren' you know all those hopes and dreams go away all of a sudden and you think 'I'm not gonna be here' and you have to deal with that and your own mortality. So you have to address those issues and help the patient realize that they have control, they can be active in their care and um, move forward and we encourage that as much as possible. Some patients don't have those coping skills and get caught in the mire of that and have difficulty making decisions and utilizing family support systems and resources, etc. Um, everybody does better when we feel like we have freedom of choice with anything..... You kinda, you kinda look at the patient's perspective and see what's the biggest worries that they have and try to give em back as much control as possible."

This patient navigator asserts that it is critical to give patient control in situations such as these because they have not only lost control of their health, but the idea that they will be able to plan for the future because they do not have any certainty that they will, in fact, be alive at that time. She also starts to speak about something physicians referred to as "decision fatigue" or an inability to make a decision due to being completely overwhelmed with the diagnosis and the reality of what is happening to them. T1 also discussed "decision fatigue"saying that she felt that this stemmed from patients feeling as though they have know control and emphasized the importance of making sure they had control as it impacts the patient's ability to make these decisions.

> "I think it's important. I don't know that everyone agrees with me, but I think it's important. It's really important. I think kind of in medicine we're really like, 'you do everything the doctor says all the time,' and now it's gone to this other way of, um, 'we're just not gonna do anything the doctor says ever and not gonna trust anything they say,' and there's some kind of happy medium in there, but I mean, I think that anyone, like our role is to sort of have this knowledge behind what our recommendations say, but people absolutely have a choice and should have a choice of what treatment they get."

T1 acknowledges that not everyone may feel that it is as important that patient's feel that they are in control, but she does feel there is a happy medium between medicine and doctors being authoritarian figures and patient's doing whatever they want because control is important and so is making knowledgeable decisions. A1 stresses the importance of giving back patient control for the purposes of strengthening them mentally.

> "Well, I try to give them as much freedom as possible. Um, because, uh, I think that strengthens then mentally and psychologically. Cause, when you talk away all of their control of their processes that is a huge hit to their psyche, their ability to withstand any event that's going to happen within the, the saga of treating the cancer"

For A1, patient control is a matter of not only strengthening the patient as a result of the trauma of the diagnosis, but also strengthening them for the process of treatment and attempting to overcome cancer. This particular physician expressed other feelings about the role of stress, in general, in bringing about the cancer. So, providing a sense of control and reducing the level of stress experienced by the patient had twofold benefits for the patient. For T5, control is also tied to information and understanding.

> "I think it's really important. I don't think any patient should be made to feel they have to try one thing. It's always good for a patient to weigh their options and to um, get a second opinion. I mean, it's totally up to the patient to make the decision and not just take someone's word for it. Totally, totally, 100% up to the patient what method of treatment they want to try. They're paying. (laughs). They're knowledgeable of what they're getting themselves into, of course they're gonna be more vocal. Most of the time patients aren't vocal because they don't really understand the aspect of what they're going through or how the treatments work. But, when they do know, you know, they have every right to decide whether they want any specific type of treatment, but again, they have to be knowledgeable of what the treatment is and how it works and all of that and most of the patients don't know all of those things."

While radiation oncologist T5 says that it is very important for patients to have a choice in their treatment, which in turn provides them with a sense of control, she also acknowledges that when people are not vocal about their choices, it tends to be because they don't fully comprehend what they are going through or the treatments. For this reason, T7 says that she really makes an effort to explain to patients exactly what is happening and why it is happening.

> "Um, when it comes, I really try and help them understand, when they're on really complicated regimens where it's you know, on day 1 we give you these exact drugs at these times and on day 2, we do these different ones or, you know, really, we have protocol sheets and I always give them a copy of it. Like, this is what we're doing. We're doing this because this is the best way to kill these cancer cells. It's really important we stay on track with this. I understand that's

> frustrating, but that's what we have to do. Because people really need to feel involved. …
> Most of our bread and butter is leukemia. A lot of other diseases can leave the doctors office, leukemia can not. Um, those patients, you will be dead in a week if we don't do chemotherapy. It's not like breast cancer where it's a couple of months, then it spreads. Leukemia, your blood IS cancer. People who have acute, acute leukemia they can die in days to weeks without treatment. It's not a 'you have a lot of time to decide' kind of thing. It's a 'we either stop it or we don't.' It's 'do you wanna get treated or no' and then you decide right now and start right now. Those are the ones that are usually the most scared and the most, since they were healthy and fine, and now they're in the hospital. But yeah, control is so important, and patients should have it. They should also have information and accurate information."

Again, T7 emphasizes the importance of control and the relationship between being informed and feeling in control. She also articulates exactly how quickly the status of a patient's health can change and how quickly treatment decisions must be made due to the seriousness of the type of cancer she most often deals with. She also offers up the possibility that patients may opt out of treatment or chose a different treatment option than the one that the doctor may be recommending. Patient navigator T6 also feels that patients should be allowed complete control of choosing any treatment option they like, regardless of what is recommended.

> "I think it's very important that they have control because it's their body, it's their health, it's their life. We're here to provide the best possible services, give them the best possible care available to them and um, and support through that, so that they do well and that's their choice. But, even, to always feel comfortable if they understand what their choices are, they still aren't feeling 'they're choosing the treatment for me.' Cause it's not for everyone."

Alternative physician, A2, though more unhappy when patients made decisions about treatment that he felt were unwise, echoed the same sentiments.

> "They have all the control. We can send a patient to treatment. We have a lot of forms as our board requires we do, in this medical state. And they can always not seek treatment. They're always informed that, every step of the process, along

> with the particular side effects, the outcome with this route or this route. And sometimes it's infuriating because patients take a route which they want to take because the think it's more beneficial for them, but it's not in our opinion because they have this thought that not having surgery will be better, but in our eyes, they have surgeries, they get better. But in the end, the patient is the boss. If they wanna not do surgery, then that's their call. But they're just jeopardizing their life, unfortunately."

When asked if he felt this should be the case (that patients have this degree of control), he went on to say:

> "Um, I'd say the majority should be their decision. They're educated, so um, at the end they should definitely be the decision makers. They have to be because it's their life, but sometimes, it's sad when you see them making wrong decisions and uh, it's too bad for them, but you can't, you can't determine treatment, that's their call. That's their call, they make that choice. If a patient doesn't want to have surgery, for example, they wanna try enemas for a month in Mexico and then you have the disease spread everywhere, well you had a curable condition, which you now can't make curable and surgery can't help you and that's sad I think, when you're, when you have a disease that gets out of control because you're not taking care of it appropriately with this model that's in place."

In spite of his feelings about the outcome when a patient chooses a course of treatment that is not the one he would prefer, because it is the patient's own life, he feels that the patient must be the one making the decisions, for better or worse, as long as they understand the consequences of their action or inaction.

For these physicians, control is tied to choice. Patients have the right, as the person who is paying and the person who is ultimately most impacted by these decisions, to make these choices about their treatment methods. As individuals who have often suddenly gone from healthy to facing their own mortality and without any certainty of a future, this choice and feeling of control is critical in helping them regain some semblance of a world that makes sense and feeling that things may become more certain again. This choice also entails the option to make the "wrong decisions"--decisions

other than the one the physician is endorsing—and also to seek a second opinion, and to inform themselves because, this understanding and self educating, helps facilitate the sense of control that these patients so badly need.

Health literacy

When asked how they felt about the impact of increased availability of health information on the internet, practitioners had mixed feelings regarding whether this was positive or negative. According to T4:

> "patients come armed with a lot more information. If they're educated, they go online and they come educated with a lot more information and so, they will know about alternative treatments and you know, and they'll ask, they'll often ask the physician questions that the physician can't answer because they haven't done as much research. They don't have as much of a vested interest. I mean, they might know a lot about a disease and they might know how to discern information about the disease better than the patient, but the patients come loaded with a lot of information. Sometimes good, sometimes not."

T4 notes that patients are able to educate themselves and have access to all types of health information and will come to appointments prepared to utilize that information in their treatment decisions. However, that information is not always sound. The type of impact this information had was often dependent on what physicians referred to as a patient's medical or health literacy. Health literacy is the degree to which patients can discern between legitimate information about health and illness, and treatment and information that is not from a trusted or reliable source.

According to T7, how medically literate a patient is and the resources they have will play a huge role in how well they deal with illness and treatment. This oncology nurse feels that health literacy is not only about accessing and utilizing the best information

resources, but also comprehending what they need to do in order to increase their chances of survival.

> "It really depends on the patient. Um, people who have high health literacy and really understand, ' I am sick. I will die if I don't follow these rules and do these things,' they are very proactive and then there are those that have appointments that we have to call and make sure they show up. It's just like people who are diabetic and die at 30 from renal failure because they won't check their blood sugar and they won't, I mean, they just won't take care of themselves cause they don't want to. It just depends on the person, it really just depends on them, cultural differences, um, and, yeah, just how much they really understand what's going on with them. The ones who have high health literacy and high income tend to be better and there are those that are low income, too, that really understand what's happening. There are people that you have to be like, "seriously, you have to go to the doctor," they'll be like, 'I don't really feel like it. I don't really care.' And it's like, well, that's not the issue. So younger people can be like that because they feel like they're invincible and 25 year olds are like, well, I'm fine, I'm 25. Older people who have the mental functioning to remember these things because they are already in that place and comfortable with it, they already have 5 specialists, so what's adding one more to the mix?"

T7 makes a connection between health literacy and self efficacy. To this practitioner, if a person has high health literacy, they comprehend the severity of their situation and the necessity of following treatment plans and coming to appointments as something necessary to their survival. To have a high level of health literacy isn't just to understand the difference between good and bad information regarding treatment on the internet, but also to understand one's mortality and the role they play in the success of the treatment by simply adhering to the doctor's orders. This falls in line with the idea in the existing literature that patients with a higher sense of self efficacy tend to be healthier. Previous research indicates that better health and greater self efficacy tends to be tied to higher income and education levels because these individuals understand what it means to take care of one's self and utilize resources (information and monetary) to

take preventative measures. To this, one would add health literacy—the ability to discern between good and bad health information. Additionally, according to T7, such a distinction between socioeconomic status and health literacy is not necessarily as accurate as a distinction by age. High and low income patients both have the capacity for high levels of health literacy and are proactive in the treatment process, however, age can be a big factor in the level of health literacy a patient has, perhaps because life and illness experience are greater.

Regardless of the level of health literacy a patient has, physicians have a mix of positive and negative feelings about the effect of this health information online. According to T7,

> "In some cases, after they get diagnosed, patients become really well informed and use that to inform their discussion with their doctor and ask more questions. Some people just read message boards and say, 'so and so had a bad experience, so I'm not gonna do it.' Um, no. That's not how science works and I'm sorry, but it depends again on health literacy and how well people understand. But the internet is, while it can be a wonderful resource, is not the same thing as getting a consult from a physician, so I think it's led people more to 'I read on the internet' instead of listening to doctors. When used correctly it can be an awesome tool for patients and their families, but too often is just they kinda do a general search and then read the first thing that pops up and have decided that they have gone to medical school, so that's not good."

T7 feels that this information can potentially have a positive effect on patient-doctor relations by allowing them to engage more in the process and make more informed decisions. However, it also has the potential to create a negative environment if patients do not understand the information they are reading. Similarly, T5 stated:

> "I don't think it affects their relationship, but I do think it can have a negative effect on how patients try to go about getting their treatment because the web—online, on websites, you know--you have a plethora of information and, a lot of it is not relevant to the patient, but they don't know what's relevant to them and

> what's not, you know people try to self-diagnose themselves on the internet, but what they're reading on the internet has nothing to do with their condition or their disease. So, it can have a negative effect on the patient. It happens all the time. It happens inside the center and outside of the center. It happens all the time."

T5 indicates that patients don't really know which information they are reading online is relevant to them and which isn't. Beyond that, they use that information to diagnose themselves which is a common problem, according to these physicians. According to T7:

> "there's always people who read the internet and say, 'the internet said,' well, the internet's not a doctor, please don't read the internet" Whenever someone starts with, "WebMD told me, I'm like, 'no, please stop.'"

A2 expresses similar sentiment to T7, saying that patients often equate online research to expertise on the matter. Patients feel that the information they have makes them as knowledgeable as the medical professionals and then the fact that it is their body in question makes them more the expert on how to best treat their illness:

> "it's bad when the patient thinks they're the doctor and um, they are overturning the doctors recommendations. So, it's not, from the way I understand it, the way it was 15, 20 years ago where you just go into a doctor's office and "trust me." Everybody now is on "doctor google" and yeah."

This physician feels that this change in access to this information has changed the doctor patient relationship, seemingly eroding the trust that was there years ago and undermining the physician's claim to expertise. In the case of his particular clinic, as mentioned previously, there are other forces at play that threaten the ability of himself as well as others at this facility to have their claims respected by their patients.

> "there's a lot of negative stuff on the internet, unfortunately about this clinic. They kind of take your word with a little hesitation, now. So, they'll definitely check what you say and uh, they'll keep on asking the same questions 3 or 4

> times sometimes, like an agent, a federal agent, which is kind of unfortunate, so, I think that's also an information issue with a lot of patients that are very sophisticated and prepared."

According to A2, it isn't just the issue of patients feeling that the health information they gained on the internet trumps the physician's expertise, but an issue of information on the internet that discredits his clinic specifically. This information creates an environment of second guessing and mistrust. A4, a physician at the same facility, said:

> "there is a lot of misinformation about us on the internet. Uh, which is founded by our competitors, uh, so I would say this is done as part of the, uh, war against us. And uh, suddenly our patients are persuaded what they see in the internet and many of them are not coming for treatment and uh, they die, so this is sad, but, there's a lot of misinformation. But unfortunately, that's a normal part of going through approval of new medications and being pioneer in certain areas."

This physician feels that this misinformation comes from traditional treatment centers and individuals who feel that his clinic is competition and seek to discredit the methods used by his clinic. Because what they are doing is new, there isn't much available information on it. They have received FDA approval and, therefore, what they are doing will become a more traditional treatment. However, in the meantime, the only information patients see is either traditional or information that speaks negatively to what they are doing at this clinic. As such, patients sometimes believe that information over the physicians at this clinic and, at times, they cease treatment, which costs them their lives.

In spite of the potential to create bad situations and negative relationships between doctors and patients, many medical professionals felt that the overall effect of accessible health information via the web was a positive one. Even after his experience

with the impact of information on the internet to his particular treatment center, A4 still feels it is important for patients to have this access and the effect is a good one.

> "It's very important because they need to understand what is their disease and they need to be somewhat educated and to try to educate them if we can and to look for various other facilities because once they know what is the disease about and what is causing the disease, they can have much more productive approach to the treatment. They can comply with the treatment regimen, they'll understand why they should take such medications. I would say the education of the patient is very important."

The education of the patient can potentially help them understand why treatment is important, how it works, and give them a general understanding of their illness. With this education, they will be a better patient and comply with what they are told is best for the sake of their health. This is ultimately more important to this physician than any of the potential problems that can arise due to the availability of such information. Even T7, who had some negative feelings about the use of this information felt that the benefits of utilizing it outweighed the risks:

> "I think it's overall been positive, yeah. In general, people can get more resources and more information. And the more resources people can get, the better. Um, sometimes it's not always accurate information and that can be a struggle, but access to information is always a good thing."

Some practitioners, like T4, felt that patients utilizing this information put patients and physicians on a more even playing field and allowed patients to not only become more active in their treatment, but also gave them more of a partnership with their physician.

> "I would say that over the last 20 years, especially since the advent of the internet, patients, uh, it's now become more of a partnership in the treatment of patients because patients, especially if they're educated, they'll do their own research. …You know, I think it's good to have a healthy exchange with a patient and be able to communicate. And to be open and honest with a patient,

> that their disease is you know, that they're gonna get better, get worse, could kill them. I think it helps to be honest."

This sharing of information and partnership between patient and physician allows for a greater honesty between them. This honesty is seen as positive for both patient and physician. T1 elaborates on the role she plays in this partnership when outside sources of information are brought up:

> "I think it's great. I mean, when people come in and say, "I read this and this and this, what do you think about this?" um, then I can give them my opinion and I can say, "here's what I think about eating soy, or whatever." And if they wanna eat soy, they can make their decision, so I think that overall it's a good thing. Again, the way my patients treat it is, "hey I looked at this and this and this" because they know I've been to school and taken a bunch of higher education classes and I sort of have a higher knowledge base than whatever blog they were on, so I think it's overall, it's a good thing."

T1 provides the expert knowledge to discern whether the information the patient brings to her is viable or not. Her role in this partnership is to let patients know if the advice they took from the internet is sound and, because they know that she has a background and education in medicine, they defer to her, as the expert. She feels that this act of verification is, in fact, exactly what these patients were seeking from her to begin with. Other health care providers felt that the availability of such information not only enabled patients to become partners with physicians in their care, but also empowered patients. A4 saw things from both the perspective of the provider and the patient:

> "Coming from the provider side, I think there's a lot of crap (laughs) out there and on the internet. But, coming from a patient, I would say, it empowers me a little bit to, if I have a diagnosis, I want to research about that as much as I could. I guess the kind of grey area in between is what is good information and what isn't, so I don't know, I think that's, that's how I feel. But I also think that patients should be able to work with the doctor and say what they think is

> affecting them and say "what do you think?" and the doctor needs to be not offended by that and um, it should be a team effort in health and I know a lot of doctors that just get really pissed off about it because, the audacity of a patient to come and tell him what to do."

A4 acknowledges that there is still the problem of being able to discern good information from information that is not high quality, but she feels that is important for patients to take control of their health by researching and making themselves as knowledgeable as possible. She emphasizes that health care should be a team effort, rather than just a patient blindly doing as they are told. She also stated that she knew doctors who were not pleased when patients did this. A1 expressed similar feelings.

> "I think it's all for the best (access to health information). There are a lot of doctors that disagree, but they're not expanding their horizons. They're just sticking with the protocol, so these things are, there's the patients who bring you something and my patients will come back and, you know, after seeing someone and say, 'I handed him a piece of paper and it was stuff I downloaded and I had questions about it and he ripped it straight out of my hand and put it straight in the trash and never did look back.' Again, you have no idea how hard that is to hear. And I had one of my patients say she pulled out some stuff that she was taking for her arthritis and the rheumatologist says 'I don't believe in that stuff. I don't like the way Dr A1 practices' and put it straight in the trash. So she said, 'well, I can see I won't be coming back here again,' you know? So, so, it's, patients learned about that glucosamine and chondroitin or whatever they're doing for their joints—exercising—they learn about that, rarely from their physicians and yet they're doing it. There's a whole lot of people doing alternative medicine and often don't tell their doctors cause they don't wanna hear or be ridiculed for it and they think doctors have knowledge they don't have, but they don't have it all. And they don't seem to be willing to try it and so, in that sense, I think it's been very empowering for patients, um, but, there's um, they find that attractive, they're tired of being subject to--and that's all it was before-- this big authoritarian that tells them what's right and you know, asks questions like "what medical school did you go to?" as if that's saying something, you know?"

He feels that taking control of one's health by utilizing this information and acting on it or bringing it into the treatment process is empowering for patients. He also feels that many physicians do not approve of patients bringing their opinions based on what they have learned to the interaction and that this disapproval stems from the idea that their authority as the expert is being challenged. This lack of openness is something that he sees as problematic and indicative of deeper problems with traditional medicine.

Other medical professionals mentioned that, with the particular population they usually dealt with, this was not a relevant issue. The people they saw most frequently at their treatment centers were described as elderly and not utilizing the internet to find information about their illness or treatment or any alternatives. As a result, these centers provided their own educational information in the form of brochures and pamphlets. These pamphlets were provided for all different reading levels and in multiple languages to ensure that all patients were able to comprehend the material. One patient navigator, T6, said that though some physicians felt that way about the older population, she disagreed.

> "I think it's had a positive impact. Um, one of our older physicians will say that most of the oncology patients are 'medicare age' cause your increased risk of cancer comes in later life and he doesn't think that those patients are open to that kind of learning, to you know, internet. But my, my experience has been, you know, it's the 60, 70 year olds that come in and you know, they did a lot of research. They come in and they're prepared when they get here and if it's not them, it's their daughter or son and they're seeking information and come with lots of questions as well."

She acknowledges that there are people that are cut off from internet resources and that she provides information for those that are, however, she does not find that it is

contingent on age. She also notes that she provides information for anyone who needs it and makes an effort to accommodate those who seek varying levels of information. Ultimately, she feels that the availability of health information has had a much more profound impact than changing the relationship between patients and physicians and empowering patients—she feels that it has had an impact on outcomes.

> "it depends on where you're at in the spectrum of care to what you see, but if you step back and see the whole picture, um, we're now being challenged to provide survivorship care and survivorship plans and cancer rehab because we have huge populations now of patients who've survived their original cancer diagnosis. Yeah, they may have some latent effects of their treatment, but we're doing better now at addressing that and helping them with a plan and you know, minimizing those kinds of things down the road for them. And 50-60 years ago, these patients wouldn't have survived and they are now. And that's, I think people realize that, that the average patient out there is a more educated consumer of health care than they used to be years ago and um, that makes it challenging sometimes –they can overwhelm themselves with bad information on the internet, but you know, it's also a good tool and I try to use it, um, judiciously, based on what their needs are."

Like others, she feels that information has it's pros and cons, but ultimately, the ability to engage with their physicians and educate themselves on what is going on with their body and the best preventative measures and ways to care for themselves has led to better outcomes. Survival rates are higher and survivorship plans are now something that is in high demand, which she sees this as being a result of the wide availability of health information.

The availability of health information on the Internet has changed the relationship between patients and physicians. For some, it has created tension in the relationship because they perceive patients to now believe that they know as much as the physicians. For others, it has enhanced the ability for patients to take an active role in

their treatment and have a more open relationship with their doctors. Ultimately, the effect that this health information has is mediated by the patient's ability to discern good information from bad, or their health literacy. If a patient has higher health literacy, then they will be more proactive in treatment and experience the positive effects that this information can have on their interactions with their physicians and ultimately, may have better outcomes from treatment.

Insurance constrains care seeking

When asked whether insurance had a constraining or enabling effect on care, all parties unanimously agreed that insurance had limited the ability to provide care rather than enhancing it. Alternative practitioner, A2, responded:

> "Definitely. Uh, we will be extremely busy if, all the callers we have, their insurance will pay. But that's not the case. We do accept insurance here, we're out of network, but it's kind of a back and forth game with the insurance. Sometimes they will pay, sometimes they won't and that leaves a lot of stress for the patient, especially those people that don't have a lot of money up front."

A2 implies that a lack of financial resources is what prevents more people from utilizing their treatment facility, as did other alternative practitioners. If the insurance will cover care, patients will obtain the treatment. If it doesn't, the patient is responsible for paying for care and, when faced with that decision, they may opt out. Traditional medical professional, T5, explicitly states that this equates to the insurance company deciding what type of treatment patient's receive, rather than the patient (if they lack resources), or even necessarily the physician..

> "Absolutely. Insurance is..they do make a lot of the decisions and a lot of the calls in the type of care the patients receive and it's up the patient if they wanna pay the extra out of pocket to get the care that they feel they should have,

> otherwise, yes, the insurance company is deciding what type of treatment they will receive."

As a result of this situation, doctors expressed frustration with the effect that insurance had on providing care. A4, the president and lead physician of an alternative treatment facility stated his feelings about insurance companies very matter of factly:

> "Insurance approach is usually avoid payment if they can and not every insurance, but there are some insurances which are encouraging patients to take the treatment, which are nice for the patient, but most of insurances are into the business of making money, so they would like to avoid payment. Regardless of patients."

A4 expressed frustration with the bottom line for insurance companies not being about patients, but rather the monetary concerns of the insurance companies, themselves. In short, greed and profit drive coverage, not concern for human life. T2, who was in charge of assisting patients with administration of their treatment and often helped them find community resources to defer the costs said:

> "Because yes, let me tell you, the insurance, oh my gosh, they give us such a hard time. Um, a lot of the newer drugs, I mean these are like 20, 30, thousand dollar drugs—yeah—and you know, they want us to turn in pathology reports, 'what's the extent of the cancer? Are you sure? Is there other alternatives? Or if there isn't other alternatives, what is the life span of the patient? What is the guaranty?' Well, nothing has a guaranty. Nothing in life, nothing. Right? And it's like, Dr X goes, 'what do you want me to say? Who's the doctor here? Are they the doctor or am I the doctor?' and its' like 'Dr. X, we have to answer all these questions, they wanna know all these things.' So, we have, they do, they really, really, really do. They will approve the drug, like I say, for 3 months, after the three months, I think most of the insurance already know, we re evaluate the patient and they ask us, 'do the patients still need to be on this drug? Can we try something else?' So that's another way that they try to tell you, 'go cheaper.' You know, but it's the cheapest you can and you know, there's some cases where they just don't even approve the drug, so we go through different alternatives and the patient, that means the patient has to go…they have to have treatment a lot longer. So we have to give 'em the second alternative, which like I said, it can be longer or it can be, like, you have to come every day. It depends, you know, it's like 'wouldn't you just rather go with the first drug?' It's like we are always

> fighting with the insurance, 'wouldn't you rather go this route? Because it would be cheaper to just come like once a month instead of daily for 7 days, then off for 3 days then off for 7 days, then daily again for 7 days?' you know because they're having to pay, you know if you look at it, it's more that way, it's more, you know? It just kills me, you know?"

As a nurse who administers and coordinates treatment, T2 is very versed in the type of questions the insurance company poses about which form of treatment is preferred by the doctor and how that clashes with the interests of the insurance company. Ultimately, the insurance company makes the final decision, even if the doctor and patient are not in agreement and even if the decision is not one the one that makes the most sense. Nurse T7 states that the care people who are uninsured or don't have private insurance receive is not only inferior, but "ridiculous."

> "Yes. Yes. It absolutely does. It plays, I don't deal with it in the sense that I don't run their insurance and I don't know what insurance covers what, but people who don't have private insurance, just have medicare or are uninsured get worse care than people who do. And more ridiculous care. More patients have to come into the hospital for things than go to the doctors office which is more expensive and uses more resources than just going to the doctors office for a shot. They have to check in to the emergency room and get admitted to the room and I have to fill out all this paper work and it's an hour to give them that 5 minute shot. They can go to the doctors office and like check in, get it, go home. Like it's ridiculous. And what insurance pays for. We do a lot of pro bono work at Hospital, especially like dialysis, mostly. We give a lot of chemo that's not paid for, but there's only so much in the budget we can do. There are patients that don't get that."

According to T7, care is inferior for these individuals or nonexistent, even when the medical need is high, as in the case of needing dialysis or chemotherapy. T2 feels that Medicaid is the worst in terms of what they provide for patient care.

> *sighs* "I think they're all the same. Every single one of them. Medicaid is the worst because, you know, I don't know, Medicaid has different, I don't know, how can I say, I don't wanna put you in a bad place, but like, it's to where, there people have cancer, you know? They have to have this treatment. Why can't they

> approve these patients, you know? This is the stuff I don't get, but yet, you know, I have nothing against it or nothing, but look at all these girls getting pregnant and they automatically qualify and these people have to go through so much before we actually get them to qualify. You know, this is their life that they're fighting for. Why? And it just kills me because these elderly that you know, of course, they have medicare, but they don't have a second income so they can't afford it and they get nothing from the government, so regardless, you're still gonna be responsible for 20% of your treatment, so I'm like go and apply for Medicaid and they're like, "well I don't qualify" and I'm like "well, why not?" and they're like "well because they say we make $12 too much and cause we own our house." And I'm like "Oh!" that's why I said, Medicaid is the worst, I think. I wish I could go to the government and be like, "you don't know what we see everyday. You don't know what we go through." I mean, some of these patients, they opt not to do anything because they can't afford it and they don't get the help that they need and you're like, "no, no, no, I'm gonna get you help. There's this foundation that will help you through this, there's this foundation that will help you for that." There's patients that don't have insurance and they don't qualify for nothing. You know, what do you do with those patients? You can't just let em slip through, you know, but they give up, you know, and that's where it hurts. I wish the government would see that in that way and, this Obamacare, people don't realize how much it's gonna hurt everybody in so many different ways. Why do you think all these doctors are going to these big groups? Cause they have to, I mean, there was no way that we were gonna be able to make it next year. There's no way Dr X would've been able to make it because they are cutting here, cutting there and they say they're supposed to be making this Obamacare for everybody to get insured, affordable insured? I heard half of these patients that are insured by Obamacare and it's not affordable. You know, 6, 7 hundred dollars a month that they're having to pay? That's still a lot of money. You would think affordable would be like 2 or 300 dollars and you know, right, and then, in order for Dr X participate, you have to do this, you have to do that, in order for him to participate in those insurance programs. There's a lot of red tape to get into those programs, to be participating, you know and he's a big specialty, so it took a lot for us to get approved and that's how this insurance is, unfortunately. And like I said, I don't wanna say nothing bad, but you have to be truthful and honest."

T2 expresses frustration with the lack of resources for patients who need care, but are unable to receive it. Her particular frustration with Medicaid and the affordable care act stems from the fact that these programs are not truly helping those who need it the most because they either do not cover needed treatment or they make coverage even

more unaffordable for those who lack resources to begin with. This frustration extends even out to the physicians who are trying to get approval under the affordable care act to provide care to those individuals. There are a lot of guidelines and many hoops to jump through in order to be able to participate.

Even in the role of provider, in attempting to give care through insurance, there were often ways that physicians and practitioners had to use loopholes to navigate through the system. For alternative practitioners, this involves utilizing traditional medicine services. Alternative A1 discusses his utilization of this method:

> "a lot of times I keep an oncologist in the loop so we can do CT/PET scans. I can do it too, but a lot of times, insurance won't cover it, if I order it. It's harder for my office to jump through all the hoops and answer all the questions and the oncologists deal with it pretty easy."

A1 is also an MD who currently practices alternative medicine in an alternative medicine clinic. So, even though he has the ability to order these tests, because of where he practices the type of medicine he practices, it is easier to simply have an oncologist who practices traditional medicine elsewhere call in the scans so that they will be covered by insurance. However, these types of hurdles are not limited to alternative physicians. Traditional medical professionals have their own barriers to providing care in such a way that it is covered by insurance. Oncology nurse T7 discusses some of this in detail.

> "It mostly has to do with what we can do with an inpatient setting versus an outpatient setting. There are a lot of times where we'll have a patient that's in with us for chemotherapy, they're doing better, they're ready to go home, but we wanna get their white blood cell count a little higher. There are a couple of options. One is to give a daily shot, called neuprogen and they have to get it once a day for between 5 and 10 days, depending. Or there's a drug called neulasta. It's one shot, one time works the same. Insurance will only pay for the one time

> one, the neulasta, as an outpatient, not an inpatient. So our option is, if the doctor says we want them to have neulasta and not have to come in every day, we discharge the patient and send a family member downstairs to readmit them. So, we typically discharge the patient with them in the room, send a family member downstairs with their insurance card to readmit them as an outpatient. And then, an hour later, once that's done, we actually discharge. And it's just to work around insurance. Because there's no medical reason it can only be done as an outpatient. It's that way with a chemo drug zulipta that's the same way, where we have to finagle with changing inpatient/outpatient status for one day and then readmit them because the insurance just wont' pay for it, but they won't admit an outpatient, even on the same day. It's ridiculous."

While these means of navigating insurance policies may be time consuming and unnecessary, they generally prove fruitful in that they allow practitioners to provide care. Unfortunately, all physicians had examples of ways that insurance affected the quality of treatment and, often the ability for a patient to receive treatment at all. Continuing with T7's experience, she discusses the way that not having private insurance can affect a patient's care.

> "yeah, we've had patients who--we had a guy who was disabled and he still had quite a bit of mental functioning, but he wasn't really able to live on his own, who had leukemia and we gave him the 60 day chemo that we talked about where there's only 60 days and he got discharged to a halfway house and because there wasn't good insurance, they had a hard time finding an oncologist who would accept his insurance. There was no lab work for awhile and so he ended up getting really sick because there was that gap, instead of it being "here's an oncologist who's gonna follow you who takes your insurance," it's "we're having a hard time finding an oncologist who takes your insurance," plus getting him to and from places because he didn't have any money. Um, so, it ended up being, instead of having that lab work afterward, he didn't get that daily lab work for awhile and so, when he finally did see somebody, he needed a blood transfusion and antibiotics. There's gaps in care when you don't have, really, it's private insurance. You have to have private insurance and or a lot of money. Those are your best options."

As previously eluded to, a lack of private insurance isn't the only thing that can negatively affect the care patients have access to. When patients reach Medicare age,

physicians note that they lose access to better care due to coverage. Alternative practitioner, A4, recalls one such patient.

> "I had a patient that had been given a year, in terms of time to survive. So, at one point, she had really great benefits and she was getting treatments on a regular basis and then she turned 65 and had to go on medicare and uh, medicare doesn't cover any of the things I do and uh, so she, she basically changed her treatment plan from coming once a week or once every other week to once every 2 weeks or every 2 months and it, sofar, her health has just declined and that just made me sick inside."

This patient was no longer able to receive alternative treatment that had been improving her health once she reached Medicare age, but traditional practitioners had similar stories. Nurse practitioner T1 relates such a story.

> "We have a patient who's got metastatic appendix cancer. It's a rare cancer, she's had it forever. We've been treating her with this oral medication and she's tolerated it well, you know, it's something you can kind of take long term, potentially and then she turned 65 and insurance went to medicare. Medicare was gonna be like $1000 a month for her, so we essentially took her off treatment, you know. She didn't wanna do the IV, so we said, "we'll take you off and keep an eye on you." And so if it comes back, we'll treat you. So that's what we did, but that was really the only thing that she tolerated well, so um, that's a rare example, but that's the one that comes to mind."

In this case, the patient came off of her traditional treatment entirely due to an inability to afford it once Medicare kicked in. However, this kind of thing is not limited to Medicare. Any care can be so costly that patients end up going without treatment, regardless of the type of coverage they have, according to Radiology Oncologist, T4.

> "Especially, with traditional medicine, some of the therapies are becoming much more expensive, insurance companies are not paying for them. Also, insurance companies, as they increase their deductibles and patients have to bear a much greater financial burden, patients are sometimes electing not to pursue, you know, traditional medicine. …They stop going to treatments or follow ups because they can't afford it and then the next time you see 'em, they're in the emergency room, you know, near death because of their situation. It's a huge factor. Huge problems with that."

This particular physician discussed problems with his own insurance covering his daughter's care.

> "Heck, even for my own, uh, experience. I have a daughter of mine that needed, her doctor just wanted to rule something out. Not that it was high on the index of suspicion, but they wanted her to go into the hospital and have a series of tests just to rule out something that was probably low on the differential diagnosis and when, you know, I said 'Fine, that's great, I've got great insurance here at this hospital,' but then they called me the Friday before the Sunday we were supposed to go and it was going to cost me $3500 out of pocket and I said, 'Hell no, we're not going!' …I wasn't gonna spend that much money for something that wasn't gonna yield that much information. But then again, I'm an exception because some people would have probably have coughed it up and probably have gotten a, a loan, or however, if they have the resources to pay for it. Others would have just said I can't do it."

Even with great insurance, T4 opts out of tests for his daughter that he doesn't feel are really necessary based on his medical expertise and the prospect of paying a large amount out of pocket, but he notes that others with less specialized knowledge would probably have gone ahead and done them. Indeed, one patient navigator, T6, told the story of a woman who, because of lack of good insurance and financial resources, in conjunction with remote location, had to raise money to get a double mastectomy when she could've easily avoided that if she'd had insurance that covered a much less extreme procedure.

> "This really bothered me. Very nice lady, helped raise her children and grandchildren, not that much older than me. Husband's on disability but also on hospice, dying of lung disease, not cancer and so, she's dealing with all of that and she has a new breast cancer and she lives out in the middle of nowhere, so driving's hard and she has this policy that's an indemnity policy. They only pay 50% or uh, $50 for doctors visits 4 times a year, $100 for a surgery and that was pretty much all her benefits and she paid almost $40 a month for that, and I couldn't even get her covered for a biopsy to get her diagnosed. But, with their disability and their social security and everything, they made just a little bit too much to qualify for breast and surgical Medicaid, so we had to work and get

> creative at helping her be able to fund her care. It was as if she was a cash paying patient without insurance, cuz it just, it didn't cover anything for her cancer care at all. I had to get her through the process to get charity care and that's torturous, too, you know, having to tell people your income and share all of your financial information, it's degrading to a lot of people. No matter how you do it, it's hard for them. So, anyhow, we got through that and you know, I talked to her surgeon, I said, 'I don't think she can finance radiation if you offer a lumpectomy, but I think if you went mastectomy, if she needs chemotherapy, we can get assistance with drugs. I could work with a local group in town called Pink Alliance to help her with the surgery and we could still give her a good outcome of not having her cancer come back for, you know, 20 years plus hopefully, versus her not doing anything, which is what she's gonna have to do.' 'I'm gonna have to just stay home and die,' she says. That always kills me when I hear that. So, was it the ideal level of care based on what her diagnosis was? Not necessarily. She wouldn't have had to had such disfiguring surgery, but was it the best that she could do with her resources and benefits that still leaves her with a house over her head and being able to care for her husband and, you know, you have to do the best that you can for that patient."

In spite of being savvy to the resources that exist in the community for individuals who are disadvantaged, T6 acknowledges that there are still those who slip through the cracks and are not able to get assistance.

> "We have a lot of patients from Mexico that have no benefits and they don't quite fit in the assistance programs and that's another case where you kinda think 'well, we can offer you this and this is what that would cost, versus this process,' same outcome you might say, but different cost ratio and you know, a lot of times they'll opt for mastectomy and even double mastectomy when they wouldn't have to because then they don't have to ever pay for a mammogram again. Women are actually making decisions like that and that, it kinda breaks my heart, but um, you know, they're doing what they have to to stay alive."

These kind of extreme measures are taken as a means of survival in the face of a lack of any other affordable option. As extreme as these types of procedures might seem, there were cases even more extreme. All practitioners from both alternative and traditional treatment centers spoke of patients who ultimately lost years of their lives as a result of inadequate insurance coverage. At one particular alternative treatment center,

patients usually seek out the treatment offered there because all other medicine has failed to help them, so insurance not paying for this care is particularly devastating. According to A3, the clinic director:

> "Oh, we see this frequently. The patient is coming to us with highly malignant brain tumor and no standard secure treatment exists and tumor is growing very fast and so it has increased four times in volume within a month, so we know that, within another month, the head of this person is literally going to explode. And the insurance refuse the payment and patient does not have any resources and the medications that are necessary for the treatment are costly and uh, we don't have resources to provide medications for the patients. They need to obtain this from the pharmacies. Insurance doesn't pay, the patient dies."

Similarly, A2, another physician at the same facility gave a specific example of another patient with a different type of cancer in similar circumstances.

> "Yeah, it's really sad. We had a young, 20 some odd year girl that was diagnosed with cervical cancer, she had great results with our treatment—complete response or near complete response, uh, but her insurance wasn't really paying a lot, so we, as a clinic, put out I think 10,000 worth for her meds, but we just couldn't do it anymore. That's just so much money. Because we don't make the medicines, and we just had to tell her, 'look, we can't do this forever.' And she went to another doctor and he helped her a little bit, but unfortunately, she didn't follow this protocol, so she passed away. So, it's sad when insurance can't pay."

In spite of efforts on the part of the facility to assist as much as possible with treatment, ultimately, a line must be drawn somewhere and, unfortunately, when that line is drawn, the cost goes beyond money and costs a life.

Physicians all agreed that insurance had a constraining rather than enabling effect on patients ability to receive care. Insurance often caused patients to not be able to receive the best traditional treatment or to receive alternative treatment at all. Practitioners mentioned that, without private insurance or their own solid financial resources, patients could expect to receive inferior treatment and physicians would have

to jump through hoops to get the insurance companies to cover it. These setbacks often led patients to take extreme measures that were unnecessary for treatment because they were the only thing they could afford, or lose years of their lives due to an inability to obtain the care they needed.

Summary

Though these medical professionals agreed on some things, such the idea that insurance had more of a constraining role on obtaining care, rather than enabling it, there was a certain level of polarization between the two branches of medicine. Traditional medical practitioners placed an emphasis on the importance of practicing what they referred to as "evidence based medicine," meaning medicine that is grounded in scientific research that has been proven through testing. Their commitment to this way of thinking made them dismissive of anything that did not fall under this paradigm; These medical professionals did feel that alternative medicine had its place--that place was simply not the curative one. In contrast, most alternative practitioners had previously been medical doctors and all were trained in both traditional and alternative medicine. These professionals were aware of the negative opinions of traditional practitioners and also acknowledged that there were certain things that were better suited for traditional physicians. While alternative practitioners were unhappy about some of the experiences they and their patients had had with traditional physicians, they seemed to be much less likely to make attempts to delegitimize the opposite branch of medicine. However, they did feel that traditional practitioners were too rigid in their commitment to "evidence based" medicine and could be "cold" and "impersonal" with their patients,

due to a more compartmentalized and bureaucratic system of practicing medicine. Indeed, traditional practitioners also acknowledged this shortcoming citing that they simply did not have the resources—primarily time—that they needed in order to effectively provide many types of support, specifically emotional support, to the patients. To this end, they provided patients with patient navigators: a free service to the patient that would help them obtain resources and support them from start of treatment to the end.

Even though physicians unanimously agreed that patients should have a high degree of control in the treatment process due to their need to restore meaning and order in a state of so much uncertainty, they did not all feel that patients had the appropriate level of health literacy needed to discern good health information from bad on the internet. This lack of health literacy has the potential to negatively impact the amount of trust that patients have in their physicians, either by way of reading negative and perhaps unfounded things about their doctors or treatment centers or by the patient coming to the conclusion that the internet knows better than their physician. The dynamic of all of these factors places the doctor patient relationship in tenuous territory as there is a struggle over which type of medicine is best; whether the patient, as the expert on their body and their symptoms or the doctor, as the medical professional, understands their illness better; a struggle with the loss of control by the patient, who is coming to terms with the illness of cancer, having to choose between a type of medicine where they will be utilizing evidence based care and receive less emotional attention or a type of medicine that is often dismissed by most because it is not what is considered

"mainstream treatment," but provides emotional support and fewer harsh side effects; and finally, the struggle to get insurance companies, who patients generally lump into a category with their physicians, to cover the treatment that patients need in order to survive. This relationship, like all relationships, consists of two parties. Therefore, in order to better understand the dynamics of this relationship and what the patient experience is with respect to these issues, future research including patient interviews should be conducted.

CHAPTER VI

SUMMARY AND CONCLUSIONS

Summary

To explore the issues surrounding doctor patient relationships, patient control in the treatment process and the perceived differences between alternative and traditional treatment centers, I conducted 10 in depth interviews with 4 alternative practitioners and 6 traditional practitioners and performed content analysis of the websites of 11 facilities or organizations that focused on cancer treatments. These websites were from 4 traditional clinics and 7 alternative clinics.

Because a diagnosis of cancer is a frightening event, the websites attempt to develop two major themes, competence and compassion, which together engender trust. Apparently aware of the positive and negative stereotypes associated their organization, the websites supply information to potential clients by appropriating positive themes from other approaches. Traditional treatment centers promote not only the science and technology that they are identified with, but also emphasize the idea of patient centered care and personalized care that they are perceived to lack, relative to alternative treatments. Simultaneously, alternative treatment centers promote their strength related to caring and commitment to more natural treatment methods, but they also promote themselves as utilizing science and technology to appeal to those who might be more drawn to that aspect of biomedical treatment. In this way, though these efforts are intended to attract those clients who might not ordinarily choose their facility, these

centers actually lose their unique identities. This process, articulated as institutional isomorphism (DiMaggio and Powell 1983) is clearly present.

These efforts to appeal to various audiences are often made not just through text, but through images. There are often representations of nature, science and technology, friendly doctors and happy patients. These images appeal to both the strengths and weaknesses (as previously mentioned) of these sites in an effort to appeal to all audiences, but they also present images of very fit, healthy bodies to an audience who is certainly unhealthy, as cancer patients generally are. These images portray an idealized body that patients may strive to obtain if they utilize the services at these treatment centers. These services are emphasized as crucial, particularly with respect to nutrition, but in reality clients must pay for these services.

Beyond that, these images of patients are happy, regardless of whether or not they have lost all of their hair to chemotherapy or are lying in a hospital bed. This image, along with the images of healthy bodies in conjunction with text about preventative measures and treatment for cancer, conveys patient obligations to Parson's sick role—the idea that once a person is ill, they assume that role, along with the obligation of exiting that role through becoming well and doing their part in the process of treatment. This includes being healthy and fit, and also cheerful, regardless of the circumstances as they "fight" cancer. At times, this emphasis goes so far as to place the majority of responsibility on the patient—even in making sure that that they are getting the correct treatment or that medical professionals have adequately sanitized their

hands—so that, according to the content of these treatment center sites, the patient has complete control over not only the treatment process, but their success in treatment.

This finding seems to reinforce the idea that patients should utilize problem focused coping techniques to be more actively involved in the care process as a partner in care, rather than a passive recipient. In turn, this also reinforces the idea that higher levels of self-efficacy or mastery will, in fact, lead to more optimal health outcomes by not only giving the patient a sense of control, but by improving patient-physician communication, which leads to greater satisfaction with care.

Beyond the images of healthy and fit bodies, the images are predominantly of younger people and vary in race and ethnicity, depending upon whether the site is alternative or traditional. Traditional treatment centers portray a wider variety of age and race on their sites—they often use stock photos of medical professionals that are more diverse than the actual staff on site—but tend to show male doctors in decision making roles and as lead physicians. Alternative treatment centers utilize predominantly stock photos of patients and those stock photos offer a striking lack of diversity, portraying their patients as well-dressed, all white heterosexual couples, wearing white, looking very happy. These images may be utilized because these sites are attempting to appeal to their target demographic, which, for alternative medicine, is a group that will be paying out of pocket for these services. Traditional treatment centers tend to have a more diverse group of patients, therefore it makes sense to try to appeal to them with more diverse stock photos.

Ironically, access to all services, traditional or CAM, is not equal. Individuals with lower socioeconomic status receive lower quality treatments and fewer screenings, which result in poorer outcomes. Because race and ethnicity are so closely related to educational attainment and income, the patterns of health care inequality are similar to those with lower socioeconomic status. These individuals generally have less access to health services, particularly primary and preventative care. In these neighborhoods, there is a lack of access to recreational facilities and stores with fresh fruits and vegetables, which makes it difficult to exercise regularly and eat a well-balanced diet—both of which are promoted by these treatment centers as aspects of patient responsibility to improve their health, prevent cancer and enhance the success of treatment. As previously mentioned, while these treatment centers emphasis the importance of nutrition and offer services to assist with proper diet, they are not free. Under a managed care system, patients who might not be as healthy due to these circumstances would then be evaluated as more costly, thus causing physicians to prescribe lower quality care in an effort to save money. Thus, even though Traditional medicine may be seen as more accessible to patients with lower socioeconomic status, the system that is put in place actually constrains physicians and puts them in a position to reproduce these class, and, by extension, race differences in access to healthcare. (Wright and Perry 2010) Simultaneously, those who do have higher socioeconomic status are better able to afford the type of treatment that individuals receive at alternative treatment centers as it is generally not covered by insurance and must be paid for out of pocket. This leads to a type of stratification in care where the majority of CAM patients

are higher SES and white, while all others receive what is covered by insurance and they can afford, which is traditional treatment.

Many of the patterns demonstrated in the websites correspond to the narratives of respondents, particularly the idea of patients taking control in the treatment process. However, the interviews illuminate some of the reasoning behind those patterns, such as the appeals to the opposite branch of medicine or the way in which traditional and alternative treatment centers portray their unique aspects (science and technology, and nature and patient centered treatment, respectively). Interviews are less guarded and less consciously organized than the website, and, as such, enable a clearer view of how participants view other organizations and those participating in those organizations.

Interviews

Interviews were conducted with 10 medical professionals at alternative and traditional treatment centers. Though these medical professionals agreed on some things, such as the idea that health insurance is more constraining than enabling with respect to obtaining treatment, there was a degree of polarization between alternative and traditional medicine. Traditional medical practitioners admitted that they were not very knowledgeable about alternative medicine and placed an emphasis on the importance of practicing "evidence based medicine," or medicine that is grounded in scientific research. Their commitment to this standard caused them to be dismissive of anything that did not fall under this paradigm. These medical professionals did feel that CAM had a place in treatment—that place was simply not curative. As stated by one oncology nurse:

> "Yeah, I think eastern medicine and western medicine have their place together. It just depends on what is wrong with you and what your goal is. If you have terminal cancer and your goal is not to cure your cancer, then by all means, please do all those other things. If your goal is to kill cancer cells, you won't do it that way."

In contrast, all alternative practitioners had training in both traditional and alternative medicine and most had previously been medical doctors or worked in traditional medicine in some capacity. This may not be true in some alternative medical sites, but it was the case in these sites where interviews occurred. These professionals were aware of the negative opinions of traditional practitioners and also acknowledged that certain illnesses were better treated by traditional medicine. Though alternative practitioners were unhappy with some personal and patient experiences with traditional physicians, they were cautious in attempting to delegitimize the opposite branch of medicine. However, they did feel that traditional practitioners were too rigid in their commitment to evidence based medicine and could be cold and impersonal with their patients, due to a more compartmentalized and bureaucratic system of practicing medicine.

Indeed, traditional practitioners acknowledged this shortcoming citing that they simply did not have the resources—primarily time—that they needed in order to effectively provide many types of support, specifically emotional support, to patients. To this end, they provided patients with patient navigators: a free service to the patient that would help them obtain resources and support them from treatment start to finish. This, of course, creates another layer of bureaucracy or further distance between physician and patient.

Even though physicians unanimously agreed that patients should have a high degree of control in the treatment to obtain meaning and order, they did not all feel that patients could discern good health information from bad on the internet. This lack of health literacy was viewed as having the potential to negatively impact the amount of trust that patients have in their physicians, either by way of reading negative and perhaps unfounded things about their doctors or treatment centers, or by the patient coming to the conclusion that the internet provides better information than the physician. In short, physicians feel that the patient having a sense of control is critical to their well-being as they move forward from diagnosis into treatment, but they don't believe that, put into practice, patients are, in reality, able to take on that control, due to their lack of expertise in medicine and treatment.

The doctor patient relationship is often at the center of a struggle over which type of medicine is best; who has the expertise on the body and their symptoms, and control over treatment and emotional support. Overlaying this dynamic are the insurance companies, and their ability to define what is and is not appropriate for payment.

Conclusions

As discussed, most studies of CAM have been done in countries outside the US, where individuals must pay for CAM out of pocket since they have universal health care. Not only is a current study in the US adding to a lacking body of literature, but it is also important at this time, as we transition from the system to which we have become so accustomed to The Patient Protection and Affordable Care Act, where CAM will continue to be an out of pocket service, but more people will, by law, be insured.

Most of the previous research has described patterns of usage rather than explore beliefs and understandings underlying motivation for use of CAM. The current research helps extend the existing research by examining the experiences of physicians and practitioners from whom those patients receive treatment, along with the context within which patients receive their treatment (traditional or nontraditional treatment facilities). This aspect of the research illuminates the ways that treatment centers utilize ideas of advances in treatment technology and personalized care to gain the trust of patients. As consumers of health care, trust is a central factor in decision making

The inclusion of the physician/practitioner perspective also adds to the existing body of literature as most studies have been one-sided and/or little to no information was provided on the extent to which conventional providers either recommended or provided access to complementary and alternative therapies. Further, it illuminates the importance of trust in patient/physician relationships and satisfaction, not only for the patient, but the physician. Trust is the foundation upon which the doctor/patient relationship is built and patients must trust the physician's orders, as well as the type of medicine they are utilizing. Physicians need patients to trust their recommendations and follow their directives in order to have a successful relationship and to progress forward through treatment effectively, which can, in turn, harbor continued trust in physicians and medicine, be it Traditional or CAM, and create healthier partnerships in treatment.

Of course, the legal and cultural setting in which medical facilities operate greatly affect those facilities. Consequently, I decided to use traditional and alternative organizations within the same state. This decision also enabled me to consider one of

the most well-known and respected traditional cancer treatment centers in the country. However, it could be that Texas is a particularly unique environment and so any generalization to other settings should be tempered. Additionally, physician perspectives are represented in the interviews. This leaves out the critical perspectives of other kinds of practitioners, or practitioners who would not advertise on websites for fear of legal repercussions. (In fact, as I noted, several times, I would arrange for interviews which would not occur because practitioners were fearful of their signatures on consent forms connecting their identity to their interview, in spite of promises of anonymity.)

Finally, for this study, I did not consider the patient. While both the physicians and the websites provide clues about what others' believe patients feel and desire, it would be important to gain patients' views directly. It is likely that patients' views of doctors are quite different from doctors' interpretation of their views.

Future research

Cancer is a highly specific context in which the consumption of CAM has particular meanings--meanings that may be very different from those observed in other disease and health contexts and serves particular roles (Broom and Tovey 2007) The core beliefs of CAM align with the way that many individuals with cancer experience illness and their bodies, as well as providing an answer to issues many of them experience with conventional medicine (Goldstein 2008). In addition, the threat of terminal illness has considerable implications for patient's preparedness to extend beyond traditional notions of evidence and effectiveness, thus making them an ideal

group for exploring the reasons for the choice of conventional or CAM treatments in the face of their illness. (Broom and Tovey 2007)

For this reason, future research should examine why individuals who have cancer choose a particular treatment.. Individuals who utilize the services of these clinics should be asked about their perception of the decision making process and how they view staff and the clinic to compare their perceptions with those intended by the facilities and the perceptions of their physicians/practitioners. Comparing those individuals who have opted for traditional treatment and those who have opted for alternative treatment methods from both the patient and physician perspective—rather than focusing on one or the other--is important because it allows for the examination of differing characteristics between the two groups, some of which (mastery and self-efficacy) have been linked to care-seeking behaviors and differing rates of health.

Because such a study will examine the doctor, staff, and patient perspective, in conjunction with the information distributed by the centers themselves, it also has the potential to improve doctor/patient communication. Doctor/patient communication is an area that has previously been highly problematic, with various calls for improvement due to patients' levels of satisfaction with care, trust/distrust of physicians, patient autonomy and disclosure of important information from patient to physician.

ENDNOTES

1.The three traditional treatment sites I had originally set out to utilize were Texas Oncology in Austin, TX; Scott & White Cancer Institute/Vasicek Cancer Treatment Center in Temple, TX; and Austin Cancer Centers in Austin, TX. The non-traditional treatment sites I planned to utilize were the Sebring clinic in Wimberly, TX; The Integrative and Functional Health Center in Rowlett, TX and the Burzynski Clinic in Houston, TX.

2.However, I was only able to recruit 3 nontraditional practitioners and 1 traditional practitioner using this strategy, with my originally proposed sites. Upon entering the field, it quickly became evident that my respondents might not be able to come from the same facilities I had proposed for several reasons. Oncologists, nurses and staff at traditional treatment facilities were very busy and not very responsive to attempts to connect for interviews. Similarly, one of the original nontraditional treatment centers I planned to draw respondents from was so understaffed that no one felt they had time for an interview.

3.In spite of the guaranty of anonymity, potential respondents were unwilling to sign a consent form for fear that it would somehow link their identity to their interview. These individuals felt that acknowledging they treated cancer would result in the larger traditional treatment centers in the area attempting to black list them or shut down their practices, and they cited stories of such incidents happening to practitioners that they knew.

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APPENDIX A

Table of Interviews

Branch of Medicine	Sex	Race	Title
Alternative	Male	White	Clinic Director/MD&NP
Alternative	Male	White	Clinic Director/MD&NP
Alternative	Male	White	MD & NP
Alternative	Female	White	TCM Doctor & Acupuncturist
Traditional	Male	White	Radiation Oncologist/Professor of Diagnostic Radiology
Traditional	Female	White	Nurse Practitioner
Traditional	Female	White	Oncology Nurse
Traditional	Female	White	Patient Navigator
Traditional	Female	African American	Radiation Therapist
Traditional	Female	Hispanic	Patient Outreach Specialist

Interview Guide

Demographic Information:(filled out by respondent)
Age:

Race/Ethnicity:

Sex:

Gender:

Highest Level of Education:

Estimated Annual Income:
___ <$20,000

___ $20,000-$50,000

___ $50,000-75,000

___$75,000-100,000

___<$100,000

Asked by researcher:

What is your job title?

What responsibilities does your job entail?

How long have you been working here?

Have you held similar positions elsewhere?

How long have you been in this particular field?

Would you say you have a personal/friendly relationship with the majority of your patients?

What is your role in the process of patient care/healing?

What drew you to this type of medicine versus alternative/traditional medicine?

Why do you think patients prefer this method of treatment/care?

Why do you prefer this method of treating illness/disease over other methods of treatment?

How knowledgeable do you feel you are about other methods of treatment/care than the one you practice?

What do you believe is the draw to other methods of treatment/care for patients?

Do you feel that your method is superior to others? (If yes, why? If no, why not?)

What degree of freedom do patients have with respect to choice in the type of therapy/treatment they receive?

How much control do patients actually have over the treatment process or decisions that are made with respect to treatment of their disease at this facility?

How important is it that patients feel they have control over their treatment?

How much control do you feel patients should have over their treatment?

Do you think that insurance benefits play a role in the amount of choice in treatment/control over the treatment process that patients experience? Why or why not?

Following up on the previous question, would you say the nature of that role is constraining? Or enabling?

Can you recall an experience with a patient that might be an example of how insurance appeared to constrain or enable a personal sense of control and choice in that patient's

treatment(if they say it's been both constraining and enabling, then ask for an example of each)?

How proactive would you say patients typically are with respect to seeking medical care for an initial diagnosis and treatment for their illness?

Do you feel that patients are satisfied with the care they receive here?

Can you recall an experience with a patient who expressed dissatisfaction with their care here and what their primary complaint was?

What did you do, personally, to try to alleviate their concern?

If their concern is not met, what is the typical outcome?

How much trust do you feel patients have in your advice/directives?

Do you feel like the amount of trust patients have in physicians/health care providers has changed over time? Why/why not?

In your opinion, what has the effect of the availability of health information on the internet been on healthcare exchanges (ie doctor/patient interaction)?

Overall, has the availability of such information had a positive or negative impact on your encounters with patients? Why do you feel that way? How can this issue best be resolved?

For the remaining questions, assume that a new patient to the clinic, whom we'll call Patient X, has recently been diagnosed with a rare form of cancer and is under your care. You have presented her with treatment options.

-In most cases, are the options you have presented an exhaustive list? If not, can you explain what you might not include and why?

-When you present the treatment options to her, do you have a preferred treatment in mind that you would like her to choose? Do you indicate your preference to her in any way?

Patient X says that she is unsure of what choice she would like to make.

-Do you offer any assistance in making that choice?

-How do you assist her in making that choice?

-In similar situations from your previous experience, what is a patient like patient X seeking from you?

Patient X chooses a treatment option that you do not necessarily feel is best.

-Do you express this feeling to patient X? why or why not?

-Regardless of the final outcome of choosing this treatment, how do you feel about the outcome of your interaction with this patient (meaning the fact that they chose a treatment option you didn't agree with)?

-In situations like these, is there anything that you wish you could change about the nature of the interaction between yourself and the patient?

Recruiting form

To Whom it May Concern:

My name is Christine McCown, PhD student in the department of Sociology at Texas A&M University. I am contacting you because I was hoping to set up some time to speak with you about your possible participation in a study I am conducting.

This study is my doctoral dissertation and seeks to illuminate the perspectives of health care professionals in the process of care and their relationships with their patients, particularly at a time when patients have become such active consumers of health care information. If you decide to participate, you will be able to choose the time and place that we will meet. I will be asking you a few questions about your perspectives and how you interact with your clients and patients. The interview time is controlled by you, but should ordinarily take around 30 minutes to an hour.

Your opinion and knowledge would provide valuable insight to this study, so I am very appreciative of your time and consideration in deciding whether or not to participate. Please contact me via email at christine.mccown00@gmail.com so that we may set up a time to discuss the possibility of your participation, along with the study, further.

Best regards,

Christine McCown

IRB Approval Form

DIVISION OF RESEARCH

Research Compliance and Biosafety

TEXAS A&M UNIVERSITY

DATE: March 03, 2015

MEMORANDUM

TO: Jane Sell, phD
TAMU - College Liberal Arts - Sociology

FROM: Dr. James Fluckey
Chair
Institutional Review Board

SUBJECT: Expedited Approval

Study Number:	IRB2014-0315D
Title:	Health Care Consumption: A study of alternative and biomedical cancer treatment centers
Approval Date:	05/23/2014
Continuing Review Due:	02/01/2016
Expiration Date:	03/01/2016

Documents Reviewed and Approved:

Submission Components			
Study Document			
Title	Version Number	Version Date	Outcome
recruitmentemailrevised	Version 1.1	05/19/2014	Approved
recruitmentemailrevised	Version 1.0	05/19/2014	Void
recruitment document 1	Version 1.1	04/30/2014	Approved
recruitment document 1	Version 1.0	04/30/2014	Void
Interview Guide for Physicians/Practitioners and Staff	Version 1.1	04/17/2014	Approved
Interview Guide for Physicians/Practitioners and Staff	Version 1.0	04/17/2014	Void
Study Consent Form			
Title	Version Number	Version Date	Outcome
Consent form	Version 1.2	04/27/2014	Approved
Consent form	Version 1.1	04/27/2014	Void

750 Agronomy Road, Suite 2701
1186 TAMU
College Station, TX 77843-1186
Tel. 979.458.1467 Fax. 979.862.3176
http://rcb.tamu.edu

Document of Consent: Written consent in accordance with 45 CF 46.116/ 21 CFR 50.27

This research project has been approved. As principal investigator, you assume the following responsibilities:

1. **Continuing Review:** The protocol must be renewed by the expiration date in order to continue with the research project. A Continuing Review application along with required documents must be submitted by the continuing review deadline. Failure to do so may result in processing delays, study termination, and/or loss of funding.
2. **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB.
3. **Unanticipated Problems and Adverse Events:** Unanticipated problems and adverse events must be reported to the IRB immediately.
4. **Reports of Potential Non-compliance:** Potential non-compliance, including deviations from protocol and violations, must be reported to the IRB office immediately.
5. **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB for review. The Amendment must be approved by the IRB before being implemented.
6. **Consent Forms:** When using a consent form or information sheet, you must use the IRB stamped approved version. Please log into iRIS to download your stamped approved version of the consenting instruments. If you are unable to locate the stamped version in iRIS, please contact the office.
7. **Audit:** Your protocol may be subject to audit by the Human Subjects Post Approval Monitor. During the life of the study please review and document study progress using the PI self-assessment found on the RCB website as a method of preparation for the potential audit. Investigators are responsible for maintaining complete and accurate study records and making them available for inspection. Investigators are encouraged to request a pre-initiation site visit with the Post Approval Monitor. These visits are designed to help ensure that all necessary documents are approved and in order prior to initiating the study and to help investigators maintain compliance.
8. **Recruitment**: All approved recruitment materials will be stamped electronically by the HSPP staff and available for download from iRIS. These IRB-stamped approved documents from iRIS must be used for recruitment. For materials that are distributed to potential participants electronically and for which you can only feasibly use the approved text rather than the stamped document, the study's IRB Protocol number, approval date, and expiration dates must be included in the following format: TAMU IRB#20XX- XXXX Approved: XX/XX/XXXX Expiration Date: XX/XX/XXXX.

1. **FERPA and PPRA:** Investigators conducting research with students must have appropriate approvals from the FERPA administrator at the institution where the research will be conducted in accordance with the Family Education Rights and Privacy Act (FERPA). The Protection of Pupil Rights Amendment (PPRA) protects the rights of parents in students ensuring that written parental consent is required for participation in surveys, analysis, or evaluation that ask questions falling into categories of protected information.
2. **Food:** Any use of food in the conduct of human subjects research must follow Texas A&M University Standard Administrative Procedure 24.01.01.M4.02.
3. **Payments:** Any use of payments to human subjects must follow Texas A&M University Standard Administrative Procedure 21.01.99.M0.03.

This electronic document provides notification of the review results by the Institutional Review Board.